

The Relationship between Dementia Family Caregivers' Traditional Values and Beliefs
about Caregiving and Well-being

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Abstract

Introduction: Canada's aging population is diverse and this diversity will continue to grow for the next two decades (Government of Canada, 2002; Katz, 2005; Statistics Canada, 2010). **Objective:** to examine the relationship between dementia family caregivers' traditionally-based beliefs about caregiving, their caregiving experience, and their well-being. **Method:** exploratory secondary data analysis of cross-sectional survey data from 76 community caregivers of persons with dementia in Ontario. **Results:** traditional values for caregiving was independently associated with coping resources and health status but not depression symptoms. Caregiver self-efficacy and social support both partially mediated the relationship between beliefs about caregiving and caregiver health status. **Discussion:** Findings from this exploratory study are consistent with stress process models of culture and caregiving. The finding that self-efficacy was associated with traditional values and that it mediated the relationship between traditional values and caregiver well-being is new to the literature.

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List of Abbreviations

α	Alpha
ADL	Activities of Daily Living
CCAC	Community Care Access Center
CES-D	Center for Epidemiologic Studies Depression Scale
CJCS	Cultural Justifications for Caregiving Scale
GTA	Greater Toronto Area
HSQ-12	Health Status Questionnaire
MAASD	Modified Autonomy Assessment Scales with Distress
MSPSS	Multidimensional Scale of Perceived Social Support
NPI	The Neuropsychiatric Inventory Questionnaire
PWD	Persons with Dementia
R	Pearson Correlation
SMAF	Functional Autonomy Measurement System

Chapter 1: Introduction

This chapter introduces the thesis topic and research questions. The main purpose of the thesis research is to examine the relationship between dementia family caregivers' culturally-based beliefs about caregiving, their caregiving experience, and their well-being. The study aims to answer the following four research questions: (1) Are traditional values for family caregiving associated with caregiver stress appraisal? (2) Are traditional values for family caregiving associated with caregiver coping resources (social support and self-efficacy)? (3) Are traditional values for family caregiving associated with caregiver well-being? and (4) Do caregiver coping resources and appraisal mediate the relationship between traditional values for family caregiving and caregiver well-being?

1.1 Problem Statement

Dementia is a term used to describe “a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged” (Alzheimer Society of Canada, 2010, p. 10). Dementia is a general term used to describe multiple types of dementias, such as Alzheimer’s disease, vascular dementia, Lewy body dementia, and Frontotemporal dementia (Touhy, Jett, Boscart, & McCleary, 2012; Alzheimer Society of Canada, 2011). Dementia is a progressive disease, where the symptoms may include impairments in: (1) memory; (2) language; (3) recognition; (4) purposeful movement; and (5) executive functioning (Alzheimer’s Association, 2012; Storandt, 2008).

The current number of Canadians living with dementia is more than 500,000 (Alzheimer’s Society of Canada, 2010). It is estimated that within one generation the number of Canadians with dementia will more than double, reaching 1.1 million. The

number of people living with dementia is going to continue to grow both in Canada and globally. Globally the prevalence of dementia doubles every 20 years which means by the year 2050 it will be reaching 115.4 million people living with dementia (Alzheimer's Society of Canada, 2011).

About half of those diagnosed with dementia remain in the community and the other half are in some type of long term care facility (CSHA, 2002). In Canada, informal caregivers account for the largest amount of dementia caregiving; this will grow from 60% to 69% over a 30 year time frame (Alzheimer Society of Canada, 2010). The amount of informal care hours is going to grow exponentially, tripling from 231 million hours per year in 2008 to 756 million hours per year in 2038 (Alzheimer Society, 2010, p. 21).

In the literature, there are two types of caregiving: (1) informal caregiving, and (2) formal caregiving. Formal caregiving typically refers to workers who are paid for the services provided (National Care Planning Council, 2012). This thesis will focus on informal or family caregiving.

Touhy, et al., (2012) estimate that "70% of care is provided to a close family member" (p. 397). Other research has indicated that the amount of in-home care provided by family members could be between 75 to 90% (Forbes & Neufeld, 2008; Guberman & Maheu, 2002). Caregiving services are paramount to Canadian society. Informal and formal caregiving services will continue to increase within Canadian society as years pass.

Diversity is part of Canadian culture and is part of Canadian identity (Touhy, et al., 2012). Canada's aging population is diverse (Government of Canada, 2002; Katz,

2005). This diversity will continue to grow in Canada for the next two decades (Statistics Canada, 2010). Statistics Canada (2010) estimates that by the year 2031 between 25-28% of the population will be foreign born or a visible minority. There will also be a shift in religious affiliation from an estimated 75% Christian currently to 65% Christian in 2031 (Touhy, et al., 2012). Immigrants account for one third of Canadians over the age of 65 (Touhy, et al., 2012). Currently, visible minorities account for 9% of the Canadian population over the age of 65 (Touhy, et al., 2012). With population aging, the proportion of older adults who are members of a visible minority is going to increase, as the 19.1% of Canadians aged 45 to 64 who are visible minorities reach old age (Touhy, et al., 2012).

1.2 Research Purpose

In order to answer the research questions, the researcher investigated a data set of community caregivers for persons with dementia (PWD), through secondary data analysis and applied quantitative analysis techniques. The community caregivers in this study are from the Greater Toronto Area (GTA) and the Niagara Region.

Ethnocultural diversity in the aging population means that it is paramount to consider ethnicity and culture for planning effective services for persons with dementia and their caregivers (Alzheimer Society of Canada, 2010). Research has been conducted about race, ethnicity, and culture in relation to dementia caregiving. However there is more research examining the relationship between race or ethnicity and dementia caregiving than there is about culture and dementia caregiving, and even less with Canadian samples. This research will contribute to a growing knowledge base of research about cultural influences and caregivers of PWD. This research highlights a Canadian

sample, which can add to the growing knowledge base and be used in future service planning.

Chapter 2: Literature Review

Through this chapter, the three topics covered include: (1) background information, which includes content on race, ethnicity, culture, and cultural values; dementia in Canada; dementia caregiving; family caregiving; and ethnicity, culture, and dementia caregiving; (2) description of theoretical models for family caregiving, culture and ethnicity focused on the model used for the thesis; and (3) summaries of research about dementia caregiving and ethnocultural variables. This chapter concludes with the research questions and hypotheses.

2.1 Background

2.1.1 Race, ethnicity, culture, and cultural values related to family

caregiving. The literature about ethnicity and culture in relation to family caregiving uses the terms culture, ethnicity, ethnocultural, and race. These terms are described here. Race is the most narrowly defined concept. Race “is based primarily upon genetically imparted physiognomical features among which skin colour is a dominant, but not the sole, attribute” (Statistics Canada, 2012, paragraph 4). In research, race is sometimes used as a marker for culture or ethnicity. However, this is a problem because of cultural and ethnic diversity within races (Pinquart & Sörensen, 2005).

Ethnicity is typically measured through reports of the person’s origin, ancestry, and race and is completed through self-reporting and through physical traits (Singh, 1997). It is not always clearly defined how ethnicity is measured in caregiving research, and this can lead to confusion (Singh, 1997). “Most of the caregiving research uses ethnic origin, race, or ethnic minority status as a proxy for the multidimensional constructs ethnicity and culture” (McCleary & Blain, 2013, p. 181). Dilworth-Anderson, et al.,

(2005) provide some examples of race as a proxy for ethnicity for dementia caregivers: Hispanic, African-American, Chinese, Asian, and European.

The related term, *visible minority*, is defined in the Employment Equity Act as “persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour” (cited by Statistics Canada, 2012, paragraph 1). According to Statistics Canada (2012), the visible minorities in Canada are: Chinese, South Asian, Black, Arab, West Asian, Filipino, Southeast Asian, Latin American, Japanese, and Korean (paragraph 1). The literature about dementia caregiving sometimes compares on the basis of visible minority status.

According to Statistics Canada (2011), ethnic origin “refers to the ethnic or cultural origins of the respondent’s ancestors. An ancestor is someone from whom a person is descended and is usually more distant than a grandparent. Ethnic origin refers to a person’s ‘roots’ and should not be confused with his or her citizenship, nationality, language or place of birth” (Statistics Canada, 2011, paragraphs 1 and 2). Ethnicity is typically measured through reports of the person’s origin, ancestry, and race and is completed through self-reporting and through physical traits (Singh, 1997).

The term *ethnocultural* is often used to refer to both ethnicity and culture. As used by the Government of Canada, ethnocultural “is defined by the shared characteristics unique to, and recognized by, that group. This includes characteristics such as cultural traditions, ancestry, language, national identity, country of origin and/or physical traits; sometimes encompassed by the term ethnocultural are groups that identify as ethnoracial or racialized” (Canada Revenue Agency, 2011, paragraph C).

Culture: “is conceptualized as a set of symbols, beliefs, and customs that shapes individual and/or group behavior” (LeVine, 1974 as cited in Dilworth-Anderson & Gibson, 2002, p. S56). Culture is learned externally and is internalized by an individual through their beliefs and behavior (Dilworth-Anderson & Gibson, 2002). The most frequently investigated cultural values in caregiving research are filial piety and familism; each will be described.

Filial piety in the literature has various definitions (Sung, 1995). Through these varying definitions two principles emerge, “to respect one’s parents and to care for one’s parents” (Sung, 1995, p. 240). Filial piety is also a “fundamental value in Confucian ethics that requires respect for parents and placing family needs over individual needs” (Knight & Sayegh, 2010). Filial piety is a key value in Asian culture; however similar values are present in other cultures and religions, but are less present (Bergman, Bodner, & Cohen-Fridel, 2012; Chappell & Kusch, 2007). In literature about caregiving, filial piety has been measured through general measures of the concept; such as the 26-item Arab-filial piety scale (AFPS) (Kahlaila & Litwin, 2011, p. 681), and, recently, through a measure developed specifically for caregivers, the Cultural Justification for Caregiving Scale (CJCS) (Dilworth-Anderson, Goodwin, & Williams, 2004). This scale, which was used in the study that provides data for the thesis research, incorporates items from several elements of cultural values, including filial piety (Dilworth-Anderson, et al., 2004).

Familism, “refers to the strong normative feelings of loyalty, dedication, reciprocity, and attachment of family members to their family and familial relationships, both nuclear and extended, as well as strong identification and solidarity with their family

members” (Heller, 1970; Sabogal, Marin, Otero-Sabogal, Marin, & Perez-Stable, 1987, as cited in Sayegh, & Knight, 2010, p. 3). Familism can be measured as a global concept; however, Knight and Sayegh (2010) describe how familism is a multidimensional concept. Familism includes the concepts of family obligation (obligation to provide caregiving for family members); support from family (expectation of support from family members when needed); and family as referents (refers to rules about how life should be lived) (Knight & Sayegh, 2010). In some of the research, familism is measured by asking about traditional versus less-traditional values about caregiving. Traditional values for caregiving incorporate expectations that family will provide care (Aranda & Knight 1997; Rozario & DeRienzi, 2008). According to Knight and Sayegh (2010), these sub-concepts of familism can have different effects on caregiving. In literature about caregiving, Knight and colleagues (2002) found that White American samples had the lowest levels of familism, followed by African American, Japanese American, Korean American, Latino American, and Korean samples. Similar to filial piety, in research about caregiving, familism has been measured through general measures of the concept, such as the Attitudinal Familism Scale (author, cited in Liu, Insel, Reed, & Crist, 2012), a fourteen-item Familism Scale (Sayegh & Knight, 2010), a nine-item Familism Scale (Losada, et al., 2010), and recently through a measure developed specifically for caregivers, the CJCS, that includes items about familism (Dilworth-Anderson, et al., 2004).

For this thesis the term ‘traditional values for caregiving’ will be used to encompass values of filial piety and familism, this can include the use of the Cultural

Justification for Caregiving Scale (CJCS). When something else is being measured or assessed in reviewed literature this will be noted.

Interestingly Knight and Sayegh (2010) discuss how research evidence has shown that obligation (familism) appears to have a negative correlation with health effects for caregivers, while conversely; family supportiveness (filial piety) appears to have a positive effect for caregiver health. If the relationships are as Knight and Sayegh (2010) propose, any study that uses a measure that incorporates filial piety and familism, such as the CJCS, could be difficult to interpret.

The thesis data set includes ethnocultural variables: ethnic origin, immigration status, religious affiliation, and the CJCS (Dilworth-Anderson, et al., 2004).

2.1.2 Dementia caregiving. About half of those diagnosed with dementia live in the community and the other half are in some type of long term care facility (Canadian Study on Health and Aging, 2002). The Alzheimer Society of Canada *Rising Tide* report (2010) indicates that “in 2008, 55% of Canadians (65 plus) with dementia were living in their own homes, most with the support of some kind of community care” (p. 19).

There is a shift now to promote staying at home and provide community care (Alzheimer’s Society of Canada, 2010). There is also a strong wish for both the individual diagnosed with dementia and the caregiver for the individual to remain in the community, in their home (Ryan, McCann, & McKenna, 2009). The *Rising Tide* report estimates that “by 2038, 62% of Canadians (65 plus) with dementia will be living in their own homes. This represents an increase of 510,000 people and would substantially increase community care and caregiver burden” (p. 19).

2.1.3 Family caregiving. This section presents information about the importance of family caregiving in Canadian society, a description of who provides family caregiving in Canada, and a description of the impact of dementia caregiving. In the literature, there are two types of caregiving: (1) informal caregiving, and (2) formal caregiving. Formal caregiving typically refers to workers who are paid for the services provided (National Care Planning Council, 2012). This thesis will focus on informal or family caregiving.

Caregivers are typically assumed to be spouses or relatives. However, this is not always the case, and caregivers can include family, friends, and neighbors (Smale & Dupuis, 2004). In Canada, 94% persons with dementia (PWD) are cared for by family or friends (Smale & Dupuis, 2004). Focusing on Ontario, it is estimated that approximately 1 million or 15% of the province's adults (aged 15-64years) are providing care for persons with dementia (Smale & Dupuis, 2004). The number of caregivers who are sixty-five or older is growing (Smale & Dupuis, 2004).

Dementia has a major impact on families, because caregiving encompasses a large amount of "time, energy and money" (Schulz & Martire, 2004, p. 240). There are some notable differences between caregivers of PWD and caregivers of older persons (Alzheimer's Association, 2012). One of the differences is that caregivers of PWD are more likely to assist with an activity of daily living, such as helping the PWD getting in and out of bed (Alzheimer's Association, 2012). Through the progression of dementia the amount of support and assistance required from family and caregivers changes over time depending on the person with dementia's needs (The Alzheimer Society of Canada, 2010).

The caregiver will usually assist the PWD in a variety of ways such as dressing, bathing, shopping, housework, taking them to doctor appointments, administering medications and many more (Schulz & Martire, 2004). These tasks can be perceived as uncomfortable and unpleasant (Schulz & Martire, 2004). As Schulz and Martire (2004) indicate “although family caregivers perform an important service for society and their relatives, they do so at considerable cost to their own well-being” (p. 242). Caregivers also have or report high incidence and prevalence of depressive and anxiety disorders or symptoms (Dunkin & Anderson-Hanley, 1998; Schulz & Martire, 2004). It is clear that caregiving can have an impact on the caregivers’ health, but can also have a negative effect on employment, income, and family finances (Alzheimer’s Association, 2012). It has been stated that the caregiver can be thought of as the ‘hidden patient,’ or ‘secondary patients’ because caregiving can be mentally, emotionally and, physically demanding for the individual (Alzheimer’s Association, 2012; Touhy, et al., 2012).

In Canada, the amount of informal care hours for persons with dementia will grow, tripling from 231 million hours per year in 2008, to 756 million hours per year in 2038 (Alzheimer Society, 2010, p. 21). As argued by Schumacher, et al., (cited in Touhy, et al., 2012), if there was no involvement from individuals providing informal care for older adults, the cost would stagger the health care system. Informal dementia caregiving has a major impact on the Canadian health system.

2.1.4 Ethnicity, culture, and dementia caregiving. It is important to understand how culturally based beliefs might influence family caregiving. Ethnocultural diversity in the aging population means that it is paramount to consider culture for planning effective services for persons with dementia and their caregivers (Alzheimer Society of Canada,

2010). Ethnicity and culture may have effects on (1) service use (Koehn, et al., 2012; Pinquart & Sörensen, 2005); (2) differences in knowledge and understanding of dementia (Koehn, et al., 2012); and (3) the meaning of caregiving (Dilworth-Anderson, Williams, and Gibson, 2002; Javenic & Connell, 2001; Milne & Chryssanthopoulou, 2005).

Differences in service utilization between ethnic groups have been noted (Koehn, et al., 2012; Pinquart & Sörensen, 2005). This may be because of cultural factors or poorly planned and inaccessible services (Koehn, et al., 2012; Pinquart & Sörensen, 2005). It is important to note that a better understanding of cultural values and its relationship to the caregiving experience is important; this is not solely through investigating ethnic minority cultures.

2.2 Theoretical Models

The purpose of this section is to describe the theoretical model of family caregiving that guides the thesis research. The search strategy to identify theoretical models is described. This section briefly notes the common models of family caregiving, culture, and ethnicity that were found to be used in research. This section concludes with a description of a theoretical model based on the stress, appraisal and coping theory (Lazarus & Folkman, 1984) that incorporates cultural variables.

Theoretical models of culture and family caregiving were identified through a search for research and theoretical literature about ethnicity, culture, and family caregiving. Searches for literature about ethnicity, culture, and caregiving were completed through Google Scholar, Medline, PsychINFO, Web of Science, and CINAHL. Theoretical models that were used in identified literature were noted. To ensure all models have been found, additional searches were conducted of Google

Scholar, Web of Science, and PsychINFO, for theoretical models or frameworks related to caregiving and culture.

The stress process theoretical model of family caregiving (and adaptations of it) is the dominant approach used to guide research about family caregiving, including research about culture, or ethnicity in relation to caregiving (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pearlin, Mullan, Semple, & Skaff, 1990). It is an adaptation of research that was completed on stress (Folkman, Lazarus, Pimeley, & Novacek, 1987; Lazarus & Folkman, 1984a; Lazarus & Folkman 1984; Pearlin & Schooler, 1979). The model has been used in other family caregiving contexts besides dementia caregiving, including mental illness (Mackay & Pakenham, 2011); attention deficit hyperactivity disorder (ADHD) (McCleary, 2002); and schizophrenia (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006).

Two theoretical models that incorporate culture or ethnicity in the stress process model of family caregiving were identified: a model of Ethnic Differences (Pinquart & Sörensen, 2005), and the Updated Sociocultural Stress and Coping Model (Knight & Sayegh, 2010).

Pinquart and Sörensen (2005) use a theoretical model of Ethnic Differences, based on Pearlin and colleagues (1990) and Kramer (1997) to organize their meta-analysis. It was not identified in any other research. This model is presented as a complex diagram, indicating many pathways of relationships. However, some of these relationships have combinations of variables placed together; coping is confounded with resources and culture. This model has an emphasis on racial differences, which is not the focus of the thesis research, but is understandable because much of the research they

based their framework on is about racial differences. The model of Ethnic Differences is not as good of a fit as the selected model.

The Updated Sociocultural Stress and Coping Model (Knight & Sayegh, 2010) is a revision based on work of Aranda and Knight (1997). According to this model, cultural values directly influence coping and social support. Coping and social support influence caregiver health. The three variables are hypothesized to differ among ethnocultural groups [social support, cultural values, and coping style]. The Updated Sociocultural Stress and Coping model is being used by several researchers for both primary research and review articles (McCallum, Longmire, & Knight, 2007; Rozario & DeRienzi, 2008; Sun, Ong, & Burnette, 2012). The theory has been used outside of dementia caregiving research to investigate attitudes toward patients with schizophrenia (Rosenfarb, Ballack, & Azizm 2006). Aspects of this model are incorporated in the thesis theoretical model, making it possible to integrate the thesis findings with existing research. However, this model does not integrate the concept of appraisal. Appraisal is at the core of the stress and coping theories. With this element missing it would be difficult to test and interpret associations.

This thesis will be guided by a theoretical model based on stress, appraisal and coping theory (Lazarus & Folkman, 1984). The thesis model includes the concept of primary and secondary stressors from the most commonly used stress-process family caregiving model (Pearlin, et al., 1990). It also includes the hypothesized direct influences of cultural values on coping and on personal coping resources and constraints in the Updated Sociocultural Stress and Coping model (Knight & Sayegh, 2010). This will allow for deeper understanding and analysis. This theoretical model was used by the

thesis supervisor and student to organize a related literature review (McCleary & Blain, 2013).

As shown in Figure 1, the diagram of the current theoretical model is visually appealing, being easy to follow the multiple pathways indicating relationships between concepts. It illustrates the large complexity and detail of stress and coping theory applied to family caregiving and it incorporates traditional values and beliefs about family caregiving. On the diagram each box represents a concept or component of the stress process model of caregiving, which is indicated in bold text; within each box are examples of selected aspects of that particular component. Arrows represent relationships between the concepts or components. The relationships which involve cultural variables are exemplified with larger arrows. Characteristics of the caregiver, specifically traditional values and beliefs about family caregiving are noted on the diagram in red text. Characteristics of the caregiver, has a round shape to quickly visualize its location and associations on the model.

Figure 1. Adaptational Theoretical Model of Family Caregiving

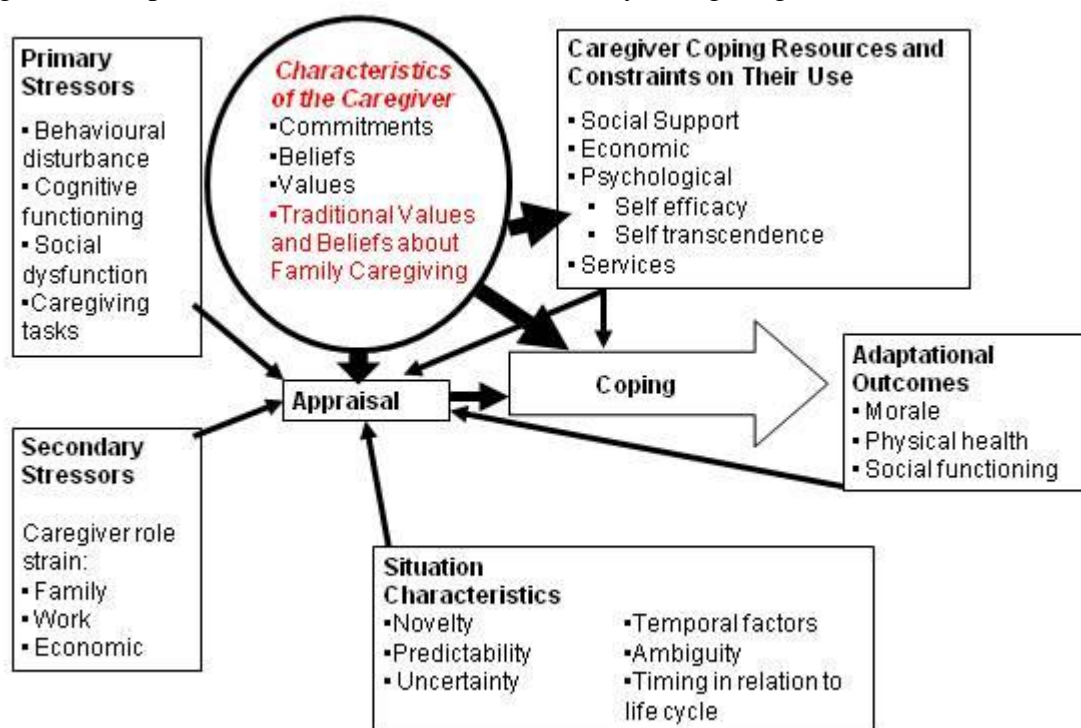


Figure 1. Stress, coping, and adaptation theory of family caregiving, including traditional values and beliefs about family caregiving. Modifications to the model, which include traditional values and beliefs about family caregiving, are represented through italics. Larger arrows in the diagram indicate relationships between traditional values and beliefs about family caregiving and other elements of the model (McCleary & Blain, 2013).

According to this model, the family caregiver's experience of appraisal and coping with the demands of caregiving starts at the left hand side with either a primary or secondary stressor. A primary stressor is changes experienced by the PWD and caregiving tasks. According to Pearlin, et al., (1990), the primary stressors can be behaviours that the PWD exhibits, cognitive changes, or changes in social functioning (e.g., wandering, forgetting, outbursts). Primary stressors can also include the number of caregiving activities as well as care recipient dependency (Pearlin, et al., 1990). A secondary stressor is role strain experienced by the caregiver because of the caregiving role.

Next, is appraisal of the stressor, where the caregiver decides either this is or is not stressful. This means that the primary or secondary stressors described earlier have the potential to be stressors for the caregiver; depending on how they are appraised by the caregiver. There are three possible outcomes of appraisal of a potential stressor: (1) irrelevant; (2) benign positive; or (3) stressful (Lazarus & Folkman, 1984). Appraisal is a cognitive process “involving judgment, discrimination, and choice of activity, based largely on past experience” (Grinkler & Spiegel, 1945, p. 122, cited in Lazarus & Folkman, 1984, p. 25). It is a two-step process. The caregiver needs to assess: (1) ‘Is the stressor a threat?’; and (2) ‘Do I have the capability and resources to manage this threat?’

The caregiver’s appraisal of a potential stressor is influenced by the caregiver’s commitments, beliefs, and values (Lazarus & Folkman, 1984). These commitments, beliefs, and values are related to culture. Culture influences appraisal. It “helps define what is important, desirable, damaging or ignorable” (Lazarus & Folkman, 1984, p. 258). According to Lazarus and Folkman (1984), the influence of culture is more apparent when the stressor occurs in “interpersonal transitions” (p. 229). Thus, it is consistent with the stress and coping theory for cultural values related to family obligations, family responsibilities, and family caregiving to be a type of value that could influence appraisal of a potential stressor.

Appraisal is also affected by characteristics of the situation in which the stressor occurs (e.g., past experience with similar stressors, predictability of the stressful situation, when it occurs in the life cycle, or other stressors). Finally, the caregiver’s appraisal is influenced by their personal coping resources, such as social support, and constraints on

using resources. Coping resources are further discussed below. Once the stressor has been appraised as stressful, the process of coping is initiated.

Coping is “effortful or purposeful thoughts and actions to manage or overcome stressful situations” (Lazarus & Folkman, 1984 and Fydenberg, 1997, as cited in Chao, 2011, p. 338). Two main kinds of coping strategies are utilized; they are referred to as: (1) emotion focused, and (2) problem focused (Lazarus & Folkman, 1984). According to Lazarus and Folkman (1984), emotion-focused coping “is directed at regulating emotional response to a problem” (p. 150) and is most likely to be used when the person believes that nothing can be done to modify a stressful situation. Emotion-focused coping strategies include approaches that lessen emotional distress (examples include, avoidance, distancing, or seeing positive value in negative events) (Lazarus & Folkman, 1984, p. 150). Emotion-focused coping may result in reappraisal of the situation as less stressful; for example a caregiver having a phone conversation with their friend about their recent role change to being a primary caregiver and talking about how demanding, but fulfilling the role is. Problem-focused coping “is directed at managing or altering the problem causing the distress” (Lazarus & Folkman, 1984, p. 150) and is most likely to be used when the person appraises the situation as “amenable to change” (p. 150). The terms emotion-focused and problem-focused coping are not always used consistently in caregiving research. Some examples of other terms include: avoidant coping (Dilworth-Anderson et al., 2002; Javenic & Connell, 2001; Knight & Sayegh, 2010); active coping (Knight & Sayegh, 2010); religious coping (Javenic & Connell, 2001); cognitive coping (Dilworth-Anderson et al., 2002; Pinquart & Sörensen, 2005); and instrumental coping (Pinquart & Sörensen, 2005). Coping, according to Lazarus and Folkman (1984), is

influenced by the caregiver's resources for coping and constraints on using resources. Resources for coping that have been identified in the caregiving literature include social support, financial resources, psychological resources such as self-efficacy for caregiving, and formal services. Constraints on resources refer to either personal constraints, which are values, and beliefs that an individual holds; or environmental constraints where competition for the same resources, agencies, and institutions occurs (Lazarus & Folkman, 1984).

In Figure 1, cultural values are shown in a separate box to illustrate relationships hypothesized in the Updated Sociocultural Stress and Coping model (Knight & Sayegh, 2010). According to that model, cultural values have a direct influence on coping and an influence on social support; one of the resources for coping in Lazarus and Folkman's theory of Stress Appraisal and Coping (1984).

As seen in Figure 1, cultural values related to family caregiving include filial piety and familism. Familism includes obligation, support from family, and family as referents. These concepts were previously described.

The final part of the process is the caregiver's adaptational outcome. Lazarus and Folkman (1984) identify three kinds of outcomes that are influenced by stress and the way that a person copes with stress: social functioning, morale or life satisfaction, and somatic health. Social functioning is typically defined as "the manner in which the individual fulfills his or her various roles" (Lazarus & Folkman, 1984, p. 183). The various roles can include but are not limited to: spouse, parent, child, job, or caregiver (Lazarus & Folkman, 1984). Sometimes social functioning can be described psychologically as satisfaction with interpersonal relationships or through having a

necessary readiness and skills (Lazarus & Folkman, 1984). Morale or life satisfaction is the second outcome that Lazarus and Folkman (1984) describe as “how people feel about themselves and their conditions of life” (p. 194). Another way that morale or life satisfaction can be understood is through concepts of happiness, satisfaction, and well-being (Lazarus & Folkman, 1984). An example of this with caregiving would be a sense of satisfaction through feelings of reciprocity. The third outcome that Lazarus and Folkman (1984) identify is somatic health which can be typically thought of as physical illness; however, evidence to support this hypothesis is not as clear. Lazarus and Folkman (1984) state “the link with illness is the conventional one, that massive bodily changes are associated with emotions, especially strong negative ones such as fear and anger” (p. 205). An example of somatic health with caregiving research could be Pinquart and Sörensen’s (2003) meta-analysis which found that there was a statistically significant, but small, difference between the levels of physical health between non-caregivers and caregivers; in favor of the non-caregivers. There was an even larger difference when testing between caregivers of PWD and non-caregivers, again in favor of the non-caregivers (Pinquart & Sörensen, 2003). This is consistent with findings of Schulz, Visintainer, and Williamson (1990), who suggested an increased vulnerability to physical illness among caregivers.

However, this is not a closed-ended model; based on the adaptational outcome it can lead to re-appraisal of the stressor. If the stressor is still perceived as stressful, it is because the coping strategy is not providing the caregiver with a state of well-being or relief from the initial stressor. This can have the caregiver change their coping method, hopefully to find a method of coping that works for them to achieve a state of well-being;

or continue through the re-appraisal process until a resolution is found. Therefore, this conceptual model represents appraisal, coping, and outcomes as a cyclic process that the caregiver may go through multiple times for the same stressor until an effective way of coping is found or the person is able to reappraise the situation as less stressful.

Using the theories and models of Lazarus and Folkman (1984), Pearlin, et al., (1990) and Knight and Sayegh (2010) allows for the findings to be integrated and comparable with other research about dementia caregiving and other research about ethnocultural factors and caregiving; it also permits for the prominent theories in the field to be utilized. In the following section, research about dementia caregiving and ethnocultural variables will be explained.

2.3 Research about Dementia Caregiving and Ethnocultural Variables

This section reviews research about dementia caregiving and ethnocultural variables. This includes (1) the search strategy used to locate the research; (2) summary of the literature; as well as (3) identification of gaps in the literature.

Literature reviews, meta-analyses, and primary research articles were identified and obtained from the Brock University Library system through computerized searches from Web of Science, CINAHL, Medline, Google Scholar, and psychINFO. Key terms used in the search strategy were dementia, Alzheimer's disease, ethnicity, caregiving, culture, cultural, ethnic, and values. The thesis supervisor and librarian assisted in developing the search strategy. Due to the large number of literature reviews and their publication dates, select primary research articles are included. Some research that measures cultural values was not included in the reviews due to publication after the dates of the reviews. Select primary research is included in the review because of this

reviews focus on cultural variables; any study that used the CJCS, or other measures of filial piety and familism are included. Select primary research articles are included because they are reports of Canadian research.

The publication type for review articles was limited to systematic reviews, literature reviews, or meta-analyses. Identified in this review are 13 narrative literature reviews, (Aranda & Knight, 1997; Braun & Browne, 1998; Botsford, Clarke, & Gibb, 2011; Chan, 2010; Connell & Gibson, 1997; Dilworth-Anderson, et al., 2002; Gonzales, Gitkin, & Lyons, 1995; Harmell, Chattillion, Roepke, & Mausbach, 2011; Javenic & Connell, 2001; Knight & Sayegh, 2010; Knight, et al., 2002; Milne & Chryssanthopoulou, 2005; Sun, et al., 2012), five systematic reviews (Cooper, Balamurali, & Livingston, 2007; Cooper, Tandy, Balamurali, & Livingston, 2010; Daker-White, Beattie, Gilliard, & Means, 2002; Nápoles, Chadiha, Eversley, & Moreno-John, 2010; Quinn, Clare, & Woods, 2010), and two meta-analyses (Cooper, et al., 2010; Pinquart & Sörensen, 2005).

Methodological quality of the reviews was considered. It was noted that there is a potential for bias in narrative reviews; for example through missing relevant available research, or not assessing the methodological quality of the research reviewed. However in some narrative reviews the methodological quality of the research included was rated (Cooper, et al., 2007; Cooper, et al., 2010). Systematic reviews and meta-analyses were assessed using Critical Appraisal Skills Programme (CASP) tool (CASP, 2010). It was found that in many cases a scoring system was not used to rate the methodological quality of research that was reviewed. Most of the reviews did not have more than one assessor to aide rigor of finding core themes in the reviewed research, with the exception

of Sun, et al., (2012). The articles reviewed were all English language except for one study that also included German (Pinquart & Sörensen, 2005). Most of the reviews included published articles, which left out unpublished documents. Also, some of the inclusion criteria in the reviews were to only include peer reviewed research. Most of the research used the main computerized databases as a means for finding research to answer their objective. Overall, searching of available studies are believable due to articles referencing many of the same research studies. The results of the reviews were similar, with some exceptions. These exceptions could be due to lack of consistency between the articles that are included in the review. These inconsistencies between articles could be due to the definition of culture differing, as well as the differing measures and methods used for analysis; making interpreting the results difficult.

Most of the primary research articles that were reviewed were cross-sectional. This method is unable to capture the true caregiving experience because it does not include the highs and lows, as well as how the caregiver copes and adapts through the process. Convenience sampling was the most common sampling method found in the research for both reviews and primary research. This results in sampling bias and limits the generalizability. The measures and methods used in the studies differed, making interpretation difficult. Within the studies, the countries and locations differed, making comparison difficult. Some studies controlled for potential confounding variables (e.g. socioeconomic status, and education) and others did not, making relating results difficult. Research available is limited for multivariate analyses, which has become a more recent research trend.

In the following sections, the organization of the literature review is guided through the stress, coping, and adaptation theory. It is presented in four subsections: (1) Cultural Values and Burden Appraisal; (2) Cultural Values and Coping Resources; (3) Cultural Values and Coping; and (4) Cultural Values and Adaptational Outcomes.

2.3.1 Cultural values and burden appraisal. Through this section research about cultural values and burden appraisal is presented. According to the stress, coping, and adaptation theoretical model of caregiving, the caregiver's appraisal of primary and secondary stressors is influenced by cultural values (a characteristic of the caregiver). Cultural factors may influence burden appraisal in two ways: (1) culture or ethnicity might be associated with whether or not the behaviours are attributed to dementia or to normal aging (which might influence the extent to which they are appraised as stressful); and (2) culture or ethnicity might influence appraisal of how stressful the dementia symptoms and behaviours are. In some of the reviewed research, it was difficult to determine whether it was cultural values or ethnicity that was being tested. Findings of review articles are presented first, followed by findings of the primary research articles.

Early research compared caregivers based on their ethnic background or race. Several reviews found that evidence about differences in stress appraisal are unclear, because of problems with research design, measurement, and failure to account for important confounding effects (Aranda & Knight, 1997; Botsford, et al., 2011; Connell & Gibson, 1997; Daker-White, et al., 2002; Dilworth-Anderson, et al., 2002).

Knight, et al., (2002) explored relationships between cultural values, caregiver burden, and caregiver depression outcomes through reviewing and summarizing individual studies that occurred in their lab. They included studies of Latino, Korean,

Korean-American, Japanese-American, African-American, and White caregivers. As expected, familism varied between ethnic groups. It was found that White and African American caregivers had lower levels of familism compared to all other ethnic groups. Mixed or inconsistent findings regarding the relationship between familism and burden occurred. In Korean and Japanese caregivers it was found that high familism related to high burden; however in Latino caregivers it was found that high familism related to lower levels of burden. This finding makes it difficult to interpret whether familism and burden are related. Knight, et al., (2002) concluded that findings indicating that familism is an explanation of burden and distress difference levels are inconsistent; findings typically do not support the hypothesis that familism is the related to these two concepts.

Aranda and Knight (1997) reviewed research on cultural values and caregiving. The review was guided through the Sociocultural Stress and Coping model described earlier. The caregivers in studies in this review were not caregivers of persons with dementia. The authors hypothesized that caregivers with higher levels of familism would have lower levels of burden because the caregiving experience would be appraised as less burdensome. Familism would also lead to differing types of coping styles and social support patterns; thus linking the cultural value of familism as an explanation for the physical and mental health outcomes of caregivers. However, the authors found little to no research to support this hypothesis about familism. Familism varied among ethnic groups reviewed.

In a more recent review, Knight and Sayegh (2010) revised the Sociocultural Stress and Coping model first presented by Aranda and Knight (1997). Through this review, research involving caregivers of persons with dementia was utilized. Knight and

Sayegh (2010) found that familism did not have an effect on caregivers of persons with dementia's burden appraisals or health outcomes. The findings do not support the complex associations between filial piety, familism, social support, and coping style that are proposed in the theory.

Conflicting results were found regarding burden in a narrative review by Janevic and Connell (2001) that reviewed research that compared two or more racial, ethnic, national, or cultural groups on aspects of dementia caregiving. This review included published peer reviewed articles from 1996 to 2000, which were able to meet the inclusion criteria. Twenty-one studies were included. Earlier research found that there was a higher burden among White caregivers compared to African American caregivers; however other research found that there was no difference. This review found that studies that investigated Korean, Chinese, and Korean American caregivers also had mixed findings for burden.

Dilworth-Anderson, et al., (2002) conducted a narrative review that included research on race, ethnicity, or culture from 1980-2000. This review was not specific to caregivers of persons with dementia. Dilworth-Anderson, et al., (2002) discuss that socially and culturally based meanings of dementia can influence caregiving experiences, understandings, and interpretation of symptoms. A limitation of the review, noted by the authors, was that culture was not well defined in the research they reviewed. There were conflicting reports of burden appraisal from the reviewed studies. Five studies found that there was a higher level for burden scores among White caregivers compared to African American caregivers. Conversely, four studies indicated that there was no difference in burden scores when comparing White and African American caregivers. When reviewing

research that was specific to caregiving for persons with dementia, it was found that there was a difference between White and African American caregivers. White caregivers had higher burden scores.

Sun, et al., (2012), conducted a systematic review with the objective to explore cultural and ethnic influences on caregiving of persons with dementia in Chinese-American families. This systematic review included published and peer reviewed articles from 1990 to early 2011. Chinese-American dementia caregivers incorporated folk models (non-biomedical terms) into their explanations of dementia; in later stages of dementia the main concern is stigma and resulting humiliation. This led to a possibility that stigma is culturally based and could increase stress appraisal. Evidence regarding filial piety and caregiver perceptions of burden, and emotional well-being were mixed.

Nápoles, et al., (2010) conducted a systematic review of published research from 1980 to 2009 on ethnic differences in caregiving of persons with dementia. Nápoles, et al., (2010) found research frequently documenting that African American caregivers experience more positive appraisals compared White caregivers. As consistent with other research on Asian-American caregivers of persons with dementia, the “most commonly found differences (compared to other ethnic groups of caregivers) related to strong beliefs of filial piety and misconceptions or stigmatization related to dementia” (Nápoles, et al., 2010, p. 394). Ethnic differences were noted at multiple levels, including appraisal.

Pinquart and Sörensen, (2005), completed a meta-analysis, which included 116 research studies, to explore ethnic differences in caregiver background variables. The research included articles on both caregiving for persons with dementia and caregiving for frail older adults. Pinquart and Sörensen, (2005) found a medium size effect in the

difference in filial obligation beliefs between ethnic minority caregivers and non-Hispanic White caregivers; meaning there are stronger beliefs among ethnic minority caregivers. The reviewers found that ethnic differences in caregiver burden can be partially explained via differences in caregiving characteristics (such as the type of illness of the care recipient, representativeness of the sample, age, or being a spouse, etc.). It was found that African American caregivers compared to White caregivers may have lower levels of burden; research available on this idea is conflicting. According to the reviews, if it is true that White caregivers have higher burden levels compared to Non-White caregivers, this could be explained by the higher proportion of spouses in White caregiving samples.

Botsford, et al., (2011) present their literature review which included examination of evidence about ethnicity and dementia caregiving. Findings include two main points: (1) evidence was found that ethnic minority caregivers and those with less formal education were more likely to adopt folk or mixed (folk and biomedical) explanations of dementia; and (2) mixed findings about the relationship between ethnicity and caregiver burden. The authors emphasized the need to consider confounding variables (socioeconomic status and education). It was found that ethnic groups view and experience dementia differently when using various explanatory models of dementia. Cultural norms and beliefs seem to influence conceptualizations of dementia, and have been suggested to have a mediating effect on caregiver well-being.

Quinn, et al., (2010) explored relationships between meanings and motivations to care (cultural beliefs) and well-being through a systematic review of peer reviewed empirical studies about dementia caregiving. A hypothesis was that a caregiver's

motivations to care could influence their well-being. The findings show that the meaning of caregiving can have a positive effect on the caregiver's well-being. Interestingly, caregivers who had higher levels of provisional meaning had lower levels of depression. "Provisional meaning (as described in the review) emerges from day to day events which give caregivers a sense of purpose from beliefs in a greater spiritual or philosophical power" (Quinn, et al., 2010, p. 45).

Now primary research is presented. Sayegh and Knight (2010) tested the updated sociocultural stress and coping model. They examined familism (familial obligation and expected support from family) and cultural justifications (CJCS) in relation to burden, coping and health of dementia caregivers. They compared African American and White caregivers using a probability sample. Two main findings from this study include: (1) univariate associations between family obligations, expected support from family, cultural justification, and burden; (2) in path models, familial obligation was associated with ethnicity. African American caregivers were more likely to perceive caregiving as an obligation than were White caregivers. This perception could possibly influence how the stressors are then appraised. However, this was not tested in the path models. Cultural justification was not associated with ethnicity.

Rozario and DeRienzi (2008) used data from the Black Rural and Urban Caregivers Mental Health Functioning study; this was cross-sectional in design and included 521 Midwestern African American women caregivers. This sample was not specific to caregivers of persons with dementia. Rozario and DeRienzi (2008) found that stronger beliefs in familism, appeared to predispose the caregivers to higher levels of psychological distress. It was also found that having more traditional beliefs about

caregiving was a significant predictor of higher perceived stress for the caregiver, after controlling for the effects of kin relationship, quality of the relationship, demographic variables, caregiver health, care recipient functioning, duration of caregiving, rural or urban location, and caregiving mastery.

Losada, et al., (2010) explored the influence of familism and dysfunctional thoughts about caregiving on depression. Dysfunctional thoughts refers to a caregiver's maladaptive way of thinking and is proposed to have a negative influence on behavioural and affective responses of caregivers. This is part of Aaron T. Beck's cognitive theory (Beck, Rush, Shaw, & Emery, 1979, as cited in Losada, et al., 2010). This study included a convenience sample of 334 caregivers of persons with dementia from Madrid and San Sebastián and was completed through face-to-face interviews. A summary score and three subscales of the Familism Scale (Sabogal, et al., 1987 cited in Losada, et al., 2010) were used: familial obligations, support from family, and family as referents. Results of the univariate analyses show that none of the Familism subscales were associated with burden.

Lai (2007; 2010) used a quantitative telephone survey method to explore Chinese-Canadian family caregivers, to investigate the relationships between filial piety and caregiver burden and appraisal of caregiving. This study included 339 participants and was not specific to caregiving for persons with dementia. In the 2007 publication, the association between filial piety and caregiver burden was tested using stepwise regression analysis. Controlling for demographic variables, health status variables, and other cultural variables (immigration status, religion, and English competence), filial piety was significantly associated with burden. However, it accounted for the smallest amount of

variance (Lai, 2007). In the 2010 publication, path analysis was used and appraisal of caregiving included three subscales: caregiver gains, value of providing care (caregiving is worthwhile), and economic costs of caregiving. Filial piety was not directly associated with caregiver burden. There was an indirect relationship. High filial piety was associated with more caregiver gains, higher values for providing care, and lower economic costs. These appraisal factors were, in turn, associated with lower levels of caregiver burden.

Liu, et al., (2012) used a cross sectional and correlation design to explore the stress, appraisal, and coping model of family caregiving among family caregivers of persons with dementia in China. The caregivers of persons with dementia were obtained from three outpatient clinics in China ($n = 96$). Through path analysis and univariate analysis, it was found that familism was not associated with caregiver subjective burden. Interestingly, it was found that familism had indirect positive effects on caregiving satisfaction.

Gray, Cucciare, & Gallagher-Thompson, (2009) explored ethnic differences in knowledge, attitudes, and beliefs about dementia among female family caregivers of persons with dementia. The sample was 215 caregivers that participated in various psycho-education programs. They compared White, Hispanic, and Chinese-American caregivers. One of the relevant findings was that Hispanic and Chinese-Americans were more likely than White caregivers to believe that memory loss is a normal part of aging. Another relevant finding was that evidence suggests that certain ethnic minorities (Hispanics, Latinos, and Chinese-Americans) are more likely to use mixed combinations of folk and biomedical models to explain Alzheimer's disease symptoms.

Dilworth-Anderson, et al., (2005) investigated relationships between caregiver characteristics and cultural justifications for caregiving (CJCS); this was not specific to caregivers of persons with dementia. This study included a convenience sample of 48 African American and 121 White caregivers. Multivariate analyses were used. They found that African Americans had stronger cultural reasons for providing care compared to Whites. In the multivariate analyses, there were significant interactions with race for both gender ($p = 0.013$) and age ($p = 0.029$). Also, multivariate analysis showed that when controlling for other caregiving characteristics, race was significantly related to the CJCS; indicating that African American caregivers scored higher on the CJCS, compared to White caregivers.

Khalaila and Litwin (2011) studied the relationships between filial piety, perceived burden, and depression in a random sample of adult children caregivers for older Arab-Israelis. (This study was not specifically focused on caregivers of persons with dementia.) Structural equation modeling was used to investigate the relationships. It was found that higher levels of filial piety were correlated with larger sized families, more needs of the recipient of care, as well as a higher number of hours spent on caregiving. It was found that higher caregiver burden was associated with lower levels of filial piety.

del-Pino-Casado, Frías-Osuna, & Palomino-Moral, (2011) used cross sectional survey. The large population-based sample ($n = 1,284$) was unique compared to the other reviewed research. The objective was to explore relationships between familism and subjective burden, among informal caregivers. This was not specific to caregivers of persons with dementia. Familism was investigated through two sub-components,

reciprocity and obligation. After controlling for caregiving duration, intensity of care, and gender, obligation was not correlated with appraisal. It was found that reciprocity was negatively associated with subjective burden.

Shurgot and Knight (2005) used a convenience sample ($n = 77$) of African American and White caregivers to assess the transactional stress and social support model. Hierarchical regression was used. A complex relationship was found. Neither ethnicity nor familism were directly associated with burden. According to the authors “African American ethnicity was associated with higher familism, which was inversely related to perceived positive support, which was associated with less burden” (p. 333).

In this section the findings were presented about two ways cultural factors might influence burden appraisal: (1) how dementia is explained (which might influence appraisal); and (2) appraisal of stress related symptoms and behaviours (burden). In summary, in the reviews there were conclusions that folk models for explaining dementia are more common in ethnic minority caregivers, which might influence stress appraisal. In the reviews, there were mixed findings about a relationship between ethnocultural factors and burden appraisal. One review found that African American caregivers had more positive appraisals than did white caregivers (Nápoles, et al., 2010). In the primary research reviewed here there were conflicting findings about differences in familism and cultural justifications for caregiving between ethnic or racial groups (Dilworth-Anderson, et al., 2005; Sayegh & Knight, 2010). Traditional beliefs about caregiving were associated with higher levels of stress in one study (Rozario & DeRienzi, 2008). Four studies found that familism was not associated with burden (del-Pino-Casado, et al., 2011; Losada, et al., 2010; Liu, et al., 2012; Shurgot & Knight, 2005). One study found

that reciprocity was negatively associated with burden (del-Pino-Casado, et al., 2011). Familism and filial piety were both correlated with satisfaction with caregiving (Lai, 2010; Liu, et al., 2012). Two studies that were not selective to dementia caregivers found that higher levels of filial piety were associated with lower levels of burden (Khalaila & Litwin, 2011; Lai, 2010).

2.3.2 Cultural values and coping resources. According to the stress, coping, and adaptation theoretical model of caregiving, cultural values have a direct relation to coping resources and constraints on their use. Coping resources include: formal or informal social support, self-efficacy, self-transcendence, and services. According to Knight and Sayegh (2010) and the Sociocultural Stress and Coping model, cultural values directly influence social support. This section will review evidence about the relationship between cultural values, race, or ethnicity – and coping resources (social support and self-efficacy.)

Early research compared caregivers based on their ethnic background or race and made comparisons of the types of social support networks that they had. There are other cultural factors that influence whether social support will be used, including both formal and informal support. One of the factors that could prevent family from obtaining support could be related to the fear of the person with dementia being labeled, leading to social stigmatization (Chan, 2010).

Findings of the reviews then primary research are presented, starting with findings from publications that were not described in the previous section. Next findings from research that has been previously discussed will be described.

Chan (2010) published a narrative review that explores the global issues of family caregiving from an Asian perspective. This review is specific to caregivers of persons with dementia. It includes published empirical studies from 1990 to 2010. Chan (2010) describes how in traditional Asian societies family is expected to take care of their older family members at their home. However, in modern Asian communities changes in demographics and socioeconomic status have led to changes in family caregiving. From the Asian perspective, social support is considered a great value, when the caregiver experiences burden. One study indicated that social support might increase self-efficacy of caregivers.

Javencic and Connell (2001) investigated research that compared two or more racial, ethnic, national, or cultural groups. This was conducted through a narrative review ($n = 21$) that was specific to caregivers of persons with dementia. Included studies were peer-reviewed publications between 1996 and 2000. Findings overall were mixed regarding social support and differences between groups. It was reported from one study that African American caregivers were less satisfied with their informal support compared to White caregivers. Conversely, another study indicated that African American caregivers were more satisfied with overall support. It was also found that there was no difference between African American and White caregivers regarding social support. African American and Latino caregivers were also found to not differ in social support. It was reported that Korean caregivers had more extended family support compared to White caregivers. United States caregivers and controls had more emotional support compared to the Chinese and control caregivers.

For the service use resource, there were differences between African American and White caregivers' perceived need for Alzheimer's Association services and, interestingly, there was no difference in Alzheimer's Association service use between these two groups. There were conflicting results found concerning formal service use. One study found that African American caregivers use more formal home care services compared to White caregivers; whereas another study noted that there was no difference between these two groups in service use.

Milne and Chryssanthopoulou (2005) conducted a review that focused on the two largest ethnic minorities in the United Kingdom, Black and Asian caregivers. This review was specific to caregivers of persons with dementia. Two studies indicate that social support significantly influences caregivers' emotional and physical well-being along with coping. The review suggested that Black and Asian have larger kinship networks compared to White caregivers.

Cooper, et al., (2010) conducted both a systematic review and meta-analysis. The research purpose was to explore dementia treatment, care, and research among different ethnic groups. It was found that ethnicity was not associated with the use of support groups, information, or referral programs. Among three studies from the United States, there was no significant difference found between ethnic groups and social service use. It was noted, from a retrospective cohort study, that African Americans used more services compared to White caregivers for in-home respite and adult day care. It was also noted that Hispanic caregivers used more in-home respite. These findings were from a program that specifically targeted ethnic minority groups.

Now, relevant findings from primary research are presented and described.

Lawrence, Murray, Samsi, and Banerjee, (2008) conducted a grounded theory study to investigate the caregiving attitudes, experiences, and needs of caregivers of persons with dementia. This study focused on the three largest ethnic groups in the United Kingdom: Black Caribbean, $n = 10$; South Asian, $n = 10$; and White British, $n = 12$. One of the emergent findings was that caregivers' attitudes towards the caregiving role itself accounted for much of the variation in the data including attitudes towards informal and formal support. These caregiving attitudes were categorized as traditional ideologies and non-traditional ideologies. It was found that caregivers with traditional ideologies were more likely to be satisfied with the addition of formal services. When looking at caregivers with non-traditional ideologies it was found that some were eager to give up caregiving responsibility, more demanding of services, and felt that their needs were not met. Interestingly, Lawrence, et al., (2008) found that many caregivers with traditional values prioritized the care recipients' needs over their own, meaning that they were choosing services that would best help the person with dementia and not themselves; therefore this impacted the amount and type of support selected.

Brummett, Siegler, Williams, Hilliard, and Dilworth-Anderson (2012) conducted a longitudinal study with data from the Alzheimer's Study of Emotions in Caregivers (ASEC). This included African American and White caregivers. The purpose of the study was to investigate perceptions of social support; this was completed at baseline and again eight years later. Overall, a main finding was that depression varied between races. Specifically, it was found that when caregivers' perceived their social support was decreased, depression rates worsened for all participants. One key difference was that

White caregivers worsened more compared to African American caregivers.

Interestingly, the CJCS was not a significant predictor of depressive symptoms.

Several of the previously described studies include findings about race, ethnicity, or cultural values in relation to coping resources. This will be presented through review articles first followed by primary research studies. Sun, et al., (2012) conducted a systematic review that focused on caregiving for persons with dementia among Chinese-American families. It was found that perceptions of dementia and filial piety (family harmony) influenced caregivers' willingness to participate in research. Cultural values affected informal support, service needs, barriers, and utilization. It was found that support from informal networks is vital to Chinese American caregivers. There was some evidence to suggest that there is a lack of family support. This lack was due to the family or the friends wanting to stay away from the person with dementia to avoid being stigmatized. A finding indicated that Chinese American caregivers used more social support compared to Chinese caregivers. It was indicated that a higher level of self-efficacy was found from the Asian perspective compared to other groups; this could be due to clear expectations of what the caregiving role is.

A narrative review that included research from 1980 to 2000 and was conducted by Dilworth-Anderson and colleagues (2002), focused on caregiving among diverse groups. One study found that African American caregivers had depression levels that were significantly lower if they received formal support. Minority caregivers had a desire or reported need for different types of formal support services; but use was similar to White caregivers. It was found that ethnic minority caregivers have more informal networks compared to White caregivers. Also, minority caregivers use informal services

similarly compared to non-minority caregivers. Interestingly, African American caregivers included God as part of their informal network of supports such as family and friends, whereas White caregivers did not.

In their meta-analysis Pinquart and Sörensen (2005) noted several studies that found African American and Latino caregivers received more support from family members compared to White caregivers. However, the opposite has also been found. Also, the authors discussed why service use, specifically formal service use, might be different or less in minority caregivers. Reasons included: language barriers, finances, cultural unacceptability of nursing homes, and less knowledge of services. A conflicting finding is present regarding the use of formal services, some research indicates that ethnic minority caregivers use less formal support and other research does not. The review notes a finding from Cox and Monk (1996, as cited in Pinquart and Sörensen, 2005), of “lower levels of support and more negative caregiving outcomes in Hispanics than African Americans” (p. 94).

Nápoles, et al., (2010) conducted a systematic review exploring ethnic differences in caregiving of persons with dementia. Ethnic differences in caregiving were present at multiple levels, including social support, and use of formal support services. Specific to African American caregivers, greater spirituality or use of prayer was evidenced. African American caregivers reported more social support. Interestingly, the systematic review indicated that the effects of ethnicity on strain may actually depend on the extent of the resources available (social support); when these resources are low all ethnic groups experience equal strain. It was found that minority caregivers are less likely to use formal support services when compared to White caregivers.

A previously described study by Shurgot and Knight (2005) assessed the transactional stress and social support model, with a sample of African American and White caregivers. A commonality among African American and White caregivers was that they were both prone to name other family members as emotional main helpers. Differences among emotional main helpers were that African American caregivers tended to list their friends, whereas White caregivers tended to list their children. “African American ethnicity was related to higher perceived social support; which was associated with decreased burden” (Shurgot & Knight, 2005, p. 333).

In conclusion, in this section findings were presented about cultural values, ethnicity, race, and coping resources. The coping resources investigated included formal support, informal support, and self-efficacy. There were mixed findings.

With respect to formal support, some studies indicated that minority caregivers use less formal support (Dilworth-Anderson, et al., 2002; Nápoles, et al., 2010; Pinquart & Sörensen, 2005). Three studies indicated that there was no difference in formal support use between African American and White caregivers (Dilworth-Anderson, et al., 2002; Javenic & Connell, 2001; Pinquart & Sörensen, 2005), while one study reported more formal service use in African American caregivers compared to White caregivers (Javenic & Connell, 2001). Three more studies in a systematic review indicated that there was no significant difference between ethnic groups and social service use (Cooper, et al., 2010).

Research about informal support also revealed conflicting findings. There were conflicting findings about whether minority caregivers had more extended networks compared to White caregivers; five studies indicated that they did (Dilworth-Anderson, et

al., 2002; Javenic & Connell, 2001; Milne & Chryssanthopoulou, 2005; Nápoles, et al., 2010; Pinquart & Sörensen, 2005); whereas Pinquart and Sörensen's (2005) meta-analysis indicated that ethnic minority caregivers may not have more extended networks. African American caregivers had lower depression if they had enough formal support (Dilworth-Anderson, et al., 2002). Both African American and White caregivers reported listing family members as emotional main helpers (Shurgot & Knight, 2005).

Unique to African American caregivers was reporting faith or God as a form of social support that was helpful or provided strength (Dilworth-Anderson, et al., 2002; Nápoles, et al., 2010). Unique to Asian culture was the idea that stigma could lead caregivers to not have enough informal support (Sun, et al., 2012).

One study found that caregivers with traditional values were more satisfied with their formal support; whereas caregivers with non-traditional values wanted more services and felt that their needs were not being fully met (Lawrence, et al., 2008). One study found that perceptions of social support did have an association with depressive rates and did differ by race (Brummett, et al., 2012).

Regarding self-efficacy there was also some discrepant findings. When looking at the Asian ethnic group it was found that they have higher self-efficacy compared to other ethnic groups (Sun, et al., 2012). Kin relationship was also associated with self-efficacy; indicating lower self-efficacy for spouses (Pinquart & Sörensen, 2005).

2.3.3 Cultural values and coping. This section reviews evidence about cultural values and coping. According to the stress, coping, and adaptation theoretical model of caregiving, cultural values directly influence coping, which was part of Knight and Sayegh's (2010) proposed relationships from the Sociocultural Stress and Coping model.

There is also an indirect relationship to coping through caregiver coping resources and constraints on their use. Cultural values also indirectly influence coping through appraisal. This section reviews evidence about the direct relationship between race, ethnicity, or cultural values and coping. This will include: (1) evidence from comparisons of ethnic groups; and (2) evidence from analyses of relationships between cultural values and coping.

This is a less detailed summary than previous sections because coping is not the focus of the thesis research. Coping was not measured in the original data collection process. Even though coping is not directly testable in the thesis, some of the information is provided for larger context and will aid in the interpretation of the findings. Findings of reviews then primary research are presented, starting with findings from publications that were not described in the previous sections. Next findings from research that has been previously discussed will be described.

It is important to note that there is not an abundant amount of research on coping among ethnic minority caregivers; unless it is African American compared to White caregivers (Dilworth-Anderson, et al., 2002).

Daker-White, et al., (2002) conducted a narrative review with the purpose of to gain knowledge about practice and guidelines about care, and provision of services for people with dementia from minority ethnic groups. This review included research published between 1985 and 1999 ($n = 67$). The main finding for coping was that non-White caregivers were more likely to use faith, religion, or prayer as a facet of coping.

Haley, et al., (1996) used an interview and questionnaire to investigate family caregivers of patients with Alzheimer's disease and other dementias through the stress

process model. The authors were interested in why Black caregivers experience less psychological distress compared to White caregivers. The sample included 123 White caregivers and 74 Black caregivers. It was found that there was not a significant difference between Black and White caregivers' coping related to church behaviours. A complex relationship was found; the effects of race on well-being were mediated through caregiver appraisals and coping responses. Two specific types of coping (avoidance coping and approach coping) in high levels were associated with higher levels of depression and lower life satisfaction. It was found that White caregivers used higher levels of both approach and avoidance coping strategies.

Several of the previously described studies and reviews include findings about relationship between race, ethnicity, or cultural values and coping. In their 20 year review, Dilworth-Anderson, et al., (2002) focused on caregiving race, ethnicity, and culture. Several racial or ethnic differences in coping were noted. American Indian caregivers were more likely to use stress management coping strategies compared to White caregivers. Conflicting results were found between African American and White caregivers regarding their type of coping used. A finding indicated that African American caregivers use more emotion focused coping compared to White caregivers. Another study indicated that there was no difference between African American and White caregivers with regards to their chosen coping strategies.

In a meta-analysis that was previously described, Pinquart and Sörensen (2005) indicated that ethnic differences in coping were observed. The reviewers classified coping strategies as cognitive, emotion-focused, or instrumental. However, they did not define these terms. It was noted that ethnic minority caregivers were more likely to use

cognitive coping and emotion-focused coping strategies. It was also found that ethnic minority caregivers did not differ from White caregivers regarding instrumental coping. In comparisons of specific ethnic minority groups, African American caregivers were more likely than White caregivers to use cognitive coping. Compared to White caregivers, Asian American caregivers were more likely to use emotion-focused coping.

In a systematic review of differences in caregiving experiences between various racial or ethnic groups, differences were found regarding spirituality and coping (Nápoles, et al., 2010). It was found for Latino caregivers that a frequent difference in coping was having greater spirituality. Among African American caregivers it was noted that there was a higher use of religious coping compared to other ethnic minority groups.

Chan (2010) found that among Asian caregivers, high burden scores were correlated with emotion-focused coping. Being less burdened was correlated with more problem-solving strategies. This review noted a finding from a study from Singapore indicating that for family caregivers of persons with dementia, religion or spirituality had positive effects on coping.

In their systematic review focusing on Chinese American caregivers Sun, et al., (2012) found that values of filial piety might assist effective coping. According to this review, when coping with distress, Chinese American caregivers use spirituality. Within Chinese American caregivers, spirituality, problem-solving, and avoidance have all been noted as potential coping mechanisms. Among both Chinese and American caregivers, problem-solving as a coping strategy appear to be beneficial as evidenced through two research studies. Overall, this review concludes that there is not sufficient evidence about the relationship between culture and coping.

Quinn, et al., (2010) systematic review explored the relationships between meanings, motivations to care, and well-being, which included coping. It was found that the concept of meaning-making was positively associated with caregiver physical health. Meaning making is a coping mechanism that some caregivers use to deal with the effects of not being able to do something that they valued or enjoyed because of the caregiving role (Quinn, et al., 2010).

Milne and Chryssanthopoulou's (2005) review from the United Kingdom focused on Black and Asian populations. It was noted that no research from the United Kingdom has specifically investigated coping responses among Black or Asian populations. However, research from the United States on African American caregivers has shown that prayer and faith are used to cope among this ethnic group.

In their review based on the revised Sociocultural Stress and Coping model, Knight and Sayegh (2010) found that African American caregivers with higher familism had higher levels of avoidant coping approaches than active coping approaches. In one study about Korean-heritage caregivers, it was found that filial piety was associated with active-cognitive coping and lower depressive symptomology. It was described that there is a possibility that latent factors of coping might not be similar across cultural groups.

Sayegh and Knight (2010) explored two factors of familism, the CJCS, and coping. It was found that familial obligation was associated with avoidant coping in all models created. Expected support from family, interestingly, was not correlated with active coping. The CJCS was significantly correlated to both active coping and avoidant coping.

Lai (2007) used a Canadian sample to explore Chinese-Canadian caregivers, investigating cultural variables. He found that caregivers who had a religion, either Western or non-Western, had higher levels of burden. The author interpreted this finding as possibly indicating that Chinese family caregivers may use religion as a coping strategy; that high burden may lead to taking up religion as a way of coping.

Liu, et al., (2012) conducted a cross-sectional correlation study to test the proposed Dementia Caregiving Model. It was found that higher familism was associated with more caregiving satisfaction, and better psychological health. It was also found that when the care recipient exhibited more frequent behavioural problems, this was linked to lower positive coping strategies.

In conclusion, this section presented findings about the ways race, ethnicity, and cultural values might influence coping. Reviews and primary research regarding coping were mixed. These mixed results could be due to studies being conducted in different countries, sample selection, as well as the measures and methods used to conduct the studies. More research is needed in this area to understand the relationship if any. Most of the research reviewed compared not on the basis of culture, but race or ethnicity.

Some research found there were differences in coping between ethnic groups, depending on type of coping (Dilworth-Anderson, et al., 2002; Pinquart and Sörensen, 2005). Other research indicated that there was no difference in coping between ethnic groups (Dilworth-Anderson, et al., 2002; Haley, et al., 1996; Pinquart & Sörensen, 2005). This could be because other variables were not controlled for. As well, ethnicity as a proxy for culture is difficult to interpret because of within group variation.

It was found that non-Whites are more likely use faith, religion, and prayer as a way of coping (Daker-White, et al., 2002; Dilworth-Anderson, et al., 2002; Milne & Chryssanthopoulou, 2005; Nápoles, et al., 2010). Among Chinese-Canadian caregivers, those with a religious affiliation had higher burden (Lai, 2007), among Asian caregivers in Singapore, religion and spirituality associated with positive coping, and among Asian caregivers, burden was associated with coping (Chan, 2010).

Associations between familism, filial piety, and the CJCS and coping were investigated in newer studies (Knight & Sayegh, 2010). It was found that filial piety and familism did have some links to types of coping (Knight & Sayegh, 2010; Liu, et al., 2012). The CJCS measure was significantly related to active and avoidant coping styles (Sayegh & Knight, 2010).

2.3.4 Cultural values and adaptational outcomes. Through this section, research about cultural variables and adaptational outcomes is presented. Outcomes that have been investigated include depression, psychological health, well-being, and perceived physical health. According to the stress, coping, and adaptation theoretical model of caregiving, the caregiver's adaptational outcomes are indirectly influenced by cultural values. Most of the research examines bivariate associations. This section will include: (1) evidence from comparisons of ethnic groups; (2) evidence from correlational studies of cultural values and caregiver outcomes; and (3) evidence of multivariate analyses of complex relationships.

Sörensen and Pinquart (2005) investigated stressors, resources, and demographic information, to explore whether or not they were differentially associated with depression symptoms and physical health depending on race and ethnicity. The sample was from a

larger REACH project (n = 1,222) and included African American, White Non-Hispanic, Hispanic Alzheimer's caregivers. One finding was that, with respect to predictors of depression and health, there were not large differences between the three ethnic groups. It was found that African American caregivers had the lowest levels of depression; while Hispanic caregivers had the highest. White caregivers had better physical health compared to African American or Hispanic caregivers. Differences across the ethnic groups in relationships with depression were found for age, income, care recipient impairments, and gender. It was found that between the ethnic groups the predictors of caregiver outcomes were similar, with a small number of exceptions (income, gender, and type of caregiver relationship).

McCallum, et al., (2007) compared African American (n = 35) and White (n = 35) female caregivers of persons with dementia with respect to variables in the sociocultural stress and coping model. A convenience sample of caregivers recruited through a research center was used and bivariate tests of differences between the racial groups were conducted. Depression symptom levels were found to be similar for both ethnic groups. The relationship between outcomes and familism was not analyzed. However, it was found that familism was not statistically significantly different between the two groups. Regarding self-rated perceived physical health there was a difference; African American caregivers reported worse physical health.

A longitudinal study conducted by Dilworth-Anderson, et al., (2004) examined whether cultural values, including the CJCS, predicted change in health status of African American caregivers. This study included 107 African American caregivers and was not specific to caregivers of persons with dementia. In the hierarchical regression analysis,

the quadratic function of cultural justifications was a significant predictor of psychosocial health. CJCS and psychosocial health had a curvilinear relationship. This indicates that the relationship between the CJCS and psychosocial health, has both caregivers scoring the lowest on the CJCS and the highest (scores ≥ 31) having lower psychosocial health at follow up. Caregivers who had moderate to strong reasons for providing care (scores between 25-31) had higher psychosocial health.

Several of the previously described studies include findings about race, ethnicity, or cultural values in relation to outcomes of caregiving. Dilworth-Anderson and colleagues' (2002) narrative review that was previously discussed included research on race, ethnicity, or culture. There were conflicting reports about depression when investigating differences between African American and White caregivers. Some research reported that depression was higher among White caregivers compared to African American caregivers (four studies); whereas other research found that there was no difference in depression level (six studies).

Conflicting results were found regarding depression in a narrative review by Janevic and Connell (2001) that reviewed research that compared two or more racial, ethnic, national, or cultural groups on aspects of dementia caregiving. Earlier research found that there was higher depression among White caregivers compared to African American caregivers. However, other research found that there was no difference. This review found that studies that investigated Korean, Chinese, and Korean-American caregivers also had mixed findings for depression. There has been speculation that "the more normative nature of caregiving in Eastern cultures may be protective against distress" (Janevic & Connell, 2001, p. 342). There is some research that supports this

hypothesis. However, the authors caution drawing any conclusions due to the limited amount of research on these ethnic groups.

Pinquart and Sörensen (2005) conducted a meta-analysis on ethnic differences, including psychological outcomes. One of the authors' hypotheses was for racial or ethnic differences in outcomes of the caregivers. This hypothesis was partially supported. There were small differences between the three ethnic groups of caregivers. Overall, it was found that ethnic minority caregivers were at an advantage with psychological health but, conversely, were disadvantaged with physical health. Specifically, it was found that the advantage for psychological health was found in African American caregivers, but not Hispanic caregivers. Asian American caregivers had lower levels of psychological health compared to White caregivers.

A review by Sun, et al., (2012) focuses on Chinese-American caregivers of persons with dementia. According to this review, there is mixed evidence about filial piety and distress and depressive symptoms of caregivers. Some of the evidence indicates that having Asian cultural beliefs is associated with lower levels of distress and depressive symptoms. Other research indicates that Asian cultural values such as filial piety can actually be a source of stress in some caregivers.

A cross-sectional study of dementia caregiving in China found a positive association between familism and psychological health (Liu, et al., 2012).

Rozario and DeRienzi (2008) found, that among African American caregivers of older adults, having more traditional caregiving beliefs was associated with more depressive symptoms.

Sayegh and Knight (2010) investigated two aspects of familism (familial obligations and expected support from family) in a probability sample of African American and White dementia caregivers. This study found that the cultural value of familism is associated with both physical and mental health of the caregiver. There was an indirect relationship between familial obligation and caregiving outcomes. Familial obligations were associated with avoidant coping (in all models); avoidant coping was then associated with poor mental and subjective physical health outcomes (Sayegh & Knight, 2010).

Losada, et al., (2010) explored the influence of familism and dysfunctional thoughts about caregiving on depression. Familial obligations (a factor of familism) were significantly correlated to depression. The relationship was positive; as familial obligation level increases so does the level of depression scores. A second relationship that was tested was between family as referents (a factor of familism) and depression. This second relationship was not significant.

In a cross-sectional study completed by Khalaila and Litwin (2011), the cultural value of filial piety was investigated among Arab-Israeli adult children caregivers. Filial piety was found to have an indirect relationship to caregiver depression. It was suggested that filial piety decreases the sense of burden; and lower burden is indirectly linked to lower depression.

In this section findings were presented about the ways that cultural factors might influence caregivers' adaptational outcomes. Overall findings regarding depression were mixed. Depression among African American and White caregiving samples is conflicting for whether there is a difference between these groups (Dilworth-Anderson, et al., 2002;

Javenic & Connell, 2001). Some research indicates that African American caregivers have more depressive symptoms when they have more traditional caregiving beliefs (Rozario & DeRienzi, 2008). Other research indicates that African American caregivers had the lowest depression, while Hispanics had the highest depression (Sörensen & Pinquart, 2005). Some research indicates that depression is similar among ethnic groups (McCallum, et al., 2007; Sörensen & Pinquart, 2005).

Conflicting depressive symptom reports are not unique to African American and White samples but also were found among Chinese American caregivers (Sun, et al., 2012). Familial obligation was related to higher depression (Losada, et al., 2010); whereas filial piety had an indirect relationship to lower depression (Khalaila & Litwin, 2011).

The adaptational outcome of psychological health had inconsistent findings among ethnic groups (Pinquart & Sörensen, 2005). Interestingly, the CJCS was found to have a curvilinear relationship to psychological health (Dilworth-Anderson, et al., 2004). Among Chinese caregivers familism appeared to have a positive association to psychological health (Liu, et al., 2012).

Physical health also contained mixed findings among ethnic groups studied (McCallum, et al., 2007; Sörensen & Pinquart, 2005). One specific finding indicated familial obligations were associated with avoidant coping; which was associated with poor mental and subjective physical health (Sayegh & Knight, 2010).

2.4 Critique of the Research

Through this section a critique of the reviews and primary research articles will be presented from the above literature review. It was noted that through the majority of the

research included convenience samples were used; this results in sampling bias and limits the generalizability of the findings. Sun, et al., (2012) indicated that perceptions about dementia and filial piety influence a caregiver's willingness to participate in research.

Also, some research controlled for confounding variables and mentioned the importance of controlling these variables (such as socioeconomic status and education) whereas other research did not (Botsford, et al., 2011); makes comparison of results difficult to interpret. Many of the studies included used simple bivariate associations (Dilworth-Anderson, et al., 2004; Liu, et al., 2012). More recent research has started to use complex statistical analyses (Brummett, et al., 2012).

Most of the research included in the reviews and primary research was cross-sectional, limiting ability to test causal associations. One study used a longitudinal design allowing for comparisons between data points adding to rigor of results obtained (Brummett, et al., 2012). Data collection was primarily obtained through self-report measures, which might include the 'hello-goodbye' effect (Streiner & Norman, 1995). This effect is when participants rate on either polar extremes of the measure to avoid an unpleasant situation, trying to qualify for services, or highlighting the severity of their situation; this would diminish the validity of the results obtained (Streiner & Norman, 1995).

The inclusion of two meta-analyses adds rigor to findings that were similar to other studies results (Cooper, et al., 2010; Pinquart & Sörensen, 2005). Also, Cooper, et al., (2010) used a scoring system to rate the research that was included in their systematic review and meta-analysis, adding rigor to the results presented. Methodological rigor was not rated in other included systematic reviews and narrative reviews. This makes

comparison of results and emergent new results tentative because the rigor of the sample, methods, and measures were not assessed. Most of the reviews only contained peer review, published, English language research. One meta-analysis did include German language research as well as English language research (Pinquart & Sörensen, 2005). The review articles used computerized searches to locate relevant research to answer their research objectives. Similar databases were used to locate the research (Medline, psychINFO, CINAHL, etc.), making it believable that all research was located from these databases. Most of the narrative reviews pointed out the methodological challenges present in the caregiving research; such as convenience sampling, lack of multivariate analysis in early research, and differences in measures used.

This review did include research that was not specific to caregivers of persons with dementia (Dilworth-Anderson, et al., 2004; Khalaila & Litwin, 2011). In these studies the stress and coping models were used to guide the research, making it probable that these findings are relevant for this review and comparable to the other included research.

The studies take place over several countries: China, Canada, United States, and United Kingdom. These differing geographic locations could potentially have different cultural values and factors associated with these areas; including health care systems and other unknown factors. If the cultural factors are different in these places, then comparison between countries is challenging.

2.5 Future Considerations

From reading the available research, there are some areas of interest for further exploration. A cultural belief study has not been completed in Canada using more than

one ethnocultural group. The CJCS is still a relatively new scale that should be assessed with a different population for reliability. The CJCS has not been found to be used in Canadian published literature.

Previous research has indicated a need for larger more representative sample of caregivers (Lai, 2007; Lai, 2010). This would allow for a causal relationship among the studied variables to be tested and re-tested through multiple samples. It has been suggested that it is important to examine the influence that cultural values have on physical and emotional health of caregivers (Pinquart & Sörensen, 2005). This would be well captured through more research taking on a longitudinal design with multiple data collection points to get a true understanding of the relationships.

2.6 Conclusions

This review of the literature found that cultural values seem to influence the caregiving experience. It was noted that there are some conflicting results, possibly due to methodological problems in the research and differences in the way elements of the stress and coping process and culture are measured.

There were conflicting about the relationship between familism and burden appraisal. Filial piety was associated with lower burden appraisal, except in research about dementia caregivers.

The reviewed research about ‘culture’ and social support, coping, and outcomes was comparisons of racial or ethnic groups, or research within one ethnic group. Cultural values were not well investigated in relationship to formal and informal social support. As mentioned previously, research was mostly about racial or ethnic differences and findings were inconclusive. Research about ethnic differences and coping, often reported

findings of differences in use of religion as a way of coping. Research about caregiver outcomes was conducted through comparisons of racial and ethnic groups, findings are inconclusive.

Some research supports the complex relationships in the theoretical model, especially for explaining caregiver outcomes (Khalaila & Litwin, 2011; Knight & Sayegh, 2010). Priorities for the current thesis are to measure cultural values and to test associations from the theoretical model.

2.7 Thesis Purpose and Research Questions

The purpose of the thesis research will examine the relationship between dementia family caregivers' values related to caregiving, their caregiving experience, and their well-being. The research questions are listed below and are controlling for the effect of education:

1. Are traditional values for family caregiving associated with caregiver stress appraisal?
2. Are traditional values for family caregiving associated with caregiver coping resources (social support and self-efficacy)?
3. Are traditional values for family caregiving associated with caregiver well-being?
4. Do caregiver coping resources and appraisal mediate the relationship between traditional values for family caregiving and caregiver well-being?

2.8 Summary

Through this chapter background information on dementia, caregiving, and culture were provided along with Canadian context statistics. Theoretical models were described and the stress, coping, and adaption model was selected for the thesis work.

Research about ethnicity, culture, and caregiving was summarized and critiqued.

Research questions and hypotheses were proposed.

Chapter 3: Research Methods

Through this chapter the thesis research methods are described. The research methods were selected in order to answer the research questions. Methods are described in detail, including (1) research design; (2) measures; and (3) analytic approach. This chapter will also include a discussion about bias for the current thesis project.

3.1 Research Design

The thesis is a secondary data analysis of cross-sectional survey data. The cross-sectional survey design was used to gather community dementia caregiver responses to various questionnaires. In the study there were two hundred and thirty-two participants. A convenience sample method was used. Recruitment was completed through various health service provider organizations located in the Greater Toronto Area (GTA) and the Niagara region; some of the services utilized included Community Care Access Center (CCAC) and senior services [for the Niagara region only]. This original study received approval by the human subjects review boards of two universities and all participants provided informed consent. Inclusion criteria for the participants included: being spouses or adult children of a family member diagnosed with a type of dementia; speaking English; and identifying themselves as the care recipient's primary care provider.

The original study was conducted by Marziali, McCleary, and Streiner (2010), with the purpose to investigate a battery of questionnaires to evaluate the personal resources and the vulnerabilities of family caregivers of persons with dementia. Selected questionnaires were included to target caregiver stress response, physical/mental health status, self-efficacy, personality, and support.

For the current thesis research, 76 participants were included for statistical analysis. This number is reduced from the original research due to the number of participants that the CJCS, the measure of cultural values, is available for. Recruitment and inclusion criteria remain the same as the original study (Marziali, et al., 2010). This study was conducted as exploratory research.

3.1.1 Secondary data. The thesis was conducted through secondary data analysis. It is paramount to describe and discuss this method of data collection. Secondary data analysis is using research data that has already been collected from a previous study (Polit & Tatano Beck, 2012). This method is used to investigate new research questions or hypotheses from the existing data (Polit & Tatano Beck, 2012). As described previously, the data for this research is obtained from a previous study (Marziali, et al., 2010). Secondary data has both benefits and limitations associated with this method as will be further described below.

Firstly, the benefits of secondary data analysis include being efficient and practical (Polit & Tatano Beck, 2012). Typically, through the research process, data collection is expensive and time consuming; (Polit & Tatano Beck, 2012; Sørensen, Sabroe, & Olsen, 1996) where this methodological choice eliminates these research obstacles. This research choice also allows for the data to continue generating new knowledge, from what was not previously analyzed but obtained in data collection process (Bibb, 2007).

There are some notable limitations to using secondary data that need to be considered. One of the limitations includes the data set itself. The data set may be incomplete in some way; this could be relating to a number of factors, such as the sample,

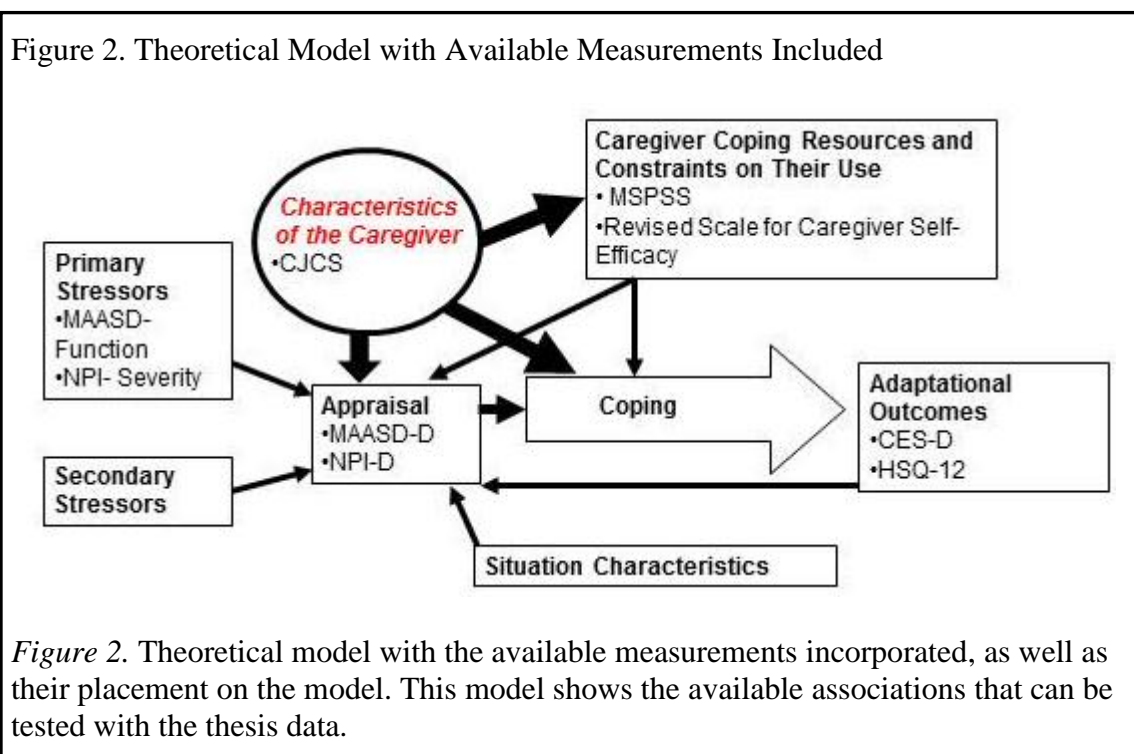
the variables used, measures collected, or others (Polit & Tatano Beck, 2012). In this case, the CJCS is not available from all participants. The CJCS scale for measuring traditional values for caregiving may be a limitation itself, since it contains items about both measures of filial piety and familism. Previous research has proposed that these two cultural values may have opposing effects (Knight & Sayegh, 2010). So using a measure that does not separate filial piety and familism components and provides an overall score may not be the ideal way to analyze these components and is a limitation. Sørensen, et al., (1996) further indicate the potential for sampling issues, in terms of selection and quality. Secondary data as a method of collection can be impossible to validate because the researcher does not have control over what was previously done (Sørensen, et al., 2006). Bibb (2007), illuminates limitations of secondary data into three sections (1) difficulty locating required data; (2) inappropriateness of primary and secondary research objectives and; (3) quality of data. In this study, the use of secondary data is efficient. Quality of the research data being used is not a concern for this study, since the data set was obtained from known sources. The use of secondary data also limits the possible research hypotheses and analyses due to the sample size and measures being predetermined.

3.2 Variables and Measures

This section describes a complete list of the variables for the current research project and how they were used, including: (1) demographic face sheet; (2) Cultural Justifications for Caregiving Scale (CJCS) (Dilworth-Anderson, et al., 2005); (3) Modified Autonomy Assessment Scales with Distress (MAASD) (Chappell, et al., 2004); (4) Neuropsychiatric Inventory (NPI) (Cummings, 1997); (5) the Multidimensional Scale

of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988); (6) Revised Scale for Caregiver Self-Efficacy (Steffen, McKibbin, Gallagher-Thompson, & Bandura, 2002); (7) Health Status Questionnaire (HSQ12) (Pettit, et al., 2001); and (8) Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977). In the thesis sample, the Cronbach alpha was calculated for each scale measure, detailed findings can be viewed on Table 1.

All measurements were provided by participants on a self-report basis with a research assistant asking the questions and recording the responses on a laptop computer. In Figure 2, a theoretical model can be visualized with the measurements inserted where the components were previously described. This can help in understanding the relationships that were tested, and what available measures there are.



3.2.1 Demographic information. The demographic face sheet has characteristics of the sample obtained and can be viewed in Appendix A. This data is provided to help in

understanding the finding and comparison of findings to other research. A couple of measures on the demographic face sheet of note that were modified in analyses are education and religious affiliation. Education was measured on a 7 point scale, with 1 being graduate professional training, and 7 being < 7 years of schooling. When analyzing this variable, 3 groups were created: (1) Post high school training, including, graduate professional training and standard college or university, were recoded as 3; (2) High school, including partial college training and high school graduate, were recoded as 2; and (3) Less than high school, including partial high school training, junior high school, and <7 years of schooling, were recoded as 1. This allowed for each recoded group of education to have a membership of greater than 1.

Religious affiliation is another item on the demographic face sheet. There were 6 choices for religious affiliation. It was noted that Protestant and Other (which included, Anglican, Wiccan, United Church, Presbyterian, Baptist, and Lutheran) are all part of Protestant faith except for Wiccan. For the analysis, Protestant and Other were coded as the same religious affiliation. The data set does not have specific affiliation information regarding the religious affiliation for the respondents who chose Other as their religious affiliation. This was a limitation of using secondary data.

3.2.2 Traditional values for caregiving. Traditional values for caregiving are values encompassing filial piety and familism. The Cultural Justifications for Caregiving Scale (CJCS) is a 10-item assessment that can be used to determine a caregiver's cultural reasoning and beliefs about providing care, or their traditional values for caregiving (Dilworth-Anderson, et al., 2005). The items include indicators of familism and filial piety. The CJCS scale includes items about reciprocity, duty, and obligation integrated in

the questionnaire. The scale is used to measure the variable traditional values for caregiving. Responses are coded using Likert-scale values ranging from one to four; one meaning strongly disagree to four meaning strongly agree. The 10-items are summed; scores can range from 10 to 40. A higher score on the CJCS is an indication of higher traditional values for providing care (Dilworth-Anderson, et al., 2005). Cronbach's alpha was 0.86 as reported by Dilworth-Anderson, et al., (2005). In this thesis sample, the Cronbach's alpha was 0.80.

Since the creation of the CJCS several researchers have used this 10-item scale as a measure in caregiving research (Dilworth-Anderson, et al., 2004; Giunta, Chow, Scharlach, & Dal Santo, 2004; Dilworth-Anderson, et al., 2005; Sayegh & Knight, 2010; Siegler, Brummett, Williams, Haney, & Dilworth-Anderson, 2010; Romero-Moreno, Márquez-González, Losada, & López, 2011; Brummett, et al., 2012). One study modified the CJCS due to previous research showing that some caregivers provided care because they had no choice; therefore this item was added to the scale (Romero-Moreno, et al., 2011). Another study modified the CJCS and used this scale as a 20-item scale (Sayegh & Knight, 2010). Giunta, et al. (2004) decided to only use some of the questions for their research.

3.2.3 Caregiver stress appraisal. Caregiver stress appraisal is the way the caregiver appraises the situation or symptoms that are present. For the thesis, stress appraisal was measured using 2 different scales: (1) the Modified Autonomy Assessment Scales with Distress (MAASD); and (2) the Neuropsychiatric Inventory (NPI), each will be described below.

3.2.3.1 Modified autonomy assessment scales with distress (MAASD). The Modified Autonomy Assessment Scales with Distress (MAASD) was used to assess the caregiver's level of distress relating to the care recipient's level of autonomy for activities of daily living (ADLs). In this study it is used as a measure of distress and was referred to as MAASD-D. This scale was modified by the researchers in the original study from the Functional Autonomy Measurement System (SMAF) (Hebert, Carrier, & Bilodeau, 1988). The modification to the scale included the addition of distress items. Cronbach's alpha for the SMAF was 0.70 and 0.80 in two samples (Chappell, et al., 2004). In this thesis sample, the Cronbach's alpha was 0.91 using the distress scores.

For the MAASD scale there are five domains: mobility (five items); activities of daily living (seven items); instrumental activities of daily living (eight items); communication (three items); and mental functions (five items). Each item is rated for level of autonomy of the care recipient. For each item there is a corresponding distress scale for participants to answer. The SMAF is scored on a 5-point scale (Hebert, Guilbault, Desrosiers, & Dubuc, 2001). The MAASD is scored on a 4-point scale. Each domain is rated similarly with 0, being no deficit (e.g. speaks normally); 1, having a small deficit (e.g. has speech/language problem but is able to express themselves); 2, has a major deficit (e.g. has major speech/language problem; able to express basic needs or answer simple questions or use sign language); 3, is unable to do task (e.g. does not communicate). From each domain a score was created, one for distress and one for function or level of autonomy of the care recipient. The scores were each created through summing the items and dividing by the number of items. For example from the five domains distress scores an overall distress score was created through dividing the scores

by five (number of domains), thus making all domains weighted equally. The same process was used for the function or level of autonomy of the care recipient. For the hierarchical regression models the distress score was utilized.

3.2.3.2 Neuropsychiatric inventory (NPI). The Neuropsychiatric Inventory (NPI) is a tool used to measure neuropsychiatric symptoms. It is used to assess behavioral disturbances among persons with dementia and caregiver distress about disturbances (Matthews, Korbey, Wilkinson, & Rowden, 2000). In this study it was used to measure distress and was referred to as NPI-D. The NPI rates 12 neuropsychiatric disturbances that are common to persons with dementia, these include: delusions; hallucinations, agitation; dysphoria; anxiety; apathy; irritability; euphoria; disinhibition; aberrant motor behaviour; night-time behaviour disturbances; as well as, appetite and eating abnormalities (Cummings, 1997, p. S10). First, caregivers indicate that a symptom is present by selecting 'yes' or 'no'. Caregivers rate on a scale for distress when the symptoms is present, and rate from 0 to 5; with 0 being not distressing at all and 5 being extreme or very severe distress. Severity is rated from 0 to 3, with 0 being not severe and 3 being severe for severity of the symptom. To score the NPI, a summary score of the symptoms present was computed through summing up the totals. A summary score of severity was computed through summing up the severity item scores. A summary score of distress was obtained through summing each the distress individual item scores (Cummings, 1997). For the 54-item NPI, an internal consistency of 0.86 was noted from del Rosario and White (2005), the NPI measure was used for the thesis did not include all 54 items. In the thesis sample, the Cronbach's alpha was 0.81 using the distress scores.

3.2.4 Caregiver coping resources. Caregiver coping resources refer to various supports for the caregiver. For this thesis social support and self-efficacy were investigated. There is one measure of social support, the Multidimensional Scale of Perceived Social Support (MSPSS) and one measure of self-efficacy, The Revised Scale for Caregiver Self-Efficacy; each will be described below.

3.2.4.1 Multidimensional scale of perceived social support (MSPSS). The Multidimensional Scale of Perceived Social Support (MSPSS) is a scale designed to measure the subjective assessment of social support adequacy (Zimet, et al., 1988). The MSPSS is a twelve-item scale. Caregivers rate their responses to each item on a Likert-scale from 1 to 5, 1 being strongly agree and 5 being strongly disagree. This scale is able to assess perceptions of social support from three different sources: family (four-items), friends (four-items), and significant other (four-items). Subscales and summary scales are calculated by summing each of the items. Cronbach's alpha for the entire scale was 0.88. Cronbach's alpha was also calculated for each subcomponent of the scale: family was 0.87; friends were 0.85; and significant other was 0.91 (Zimet, et al., 1988). This indicates that from all aspects the MSPSS demonstrates good internal consistency. For the current study the overall scale was used. In the thesis sample, the Cronbach's alpha was 0.89.

3.2.4.2 Revised scale for caregiver self-efficacy. The Revised Scale for Caregiver Self-Efficacy is a fifteen-item scale (Steffen, et al., 2002). This scale asks caregivers to rate their level of confidence in their ability when giving their best effort to complete the activity; this is done as a percent (0 to 100). This scale measures caregiving self-efficacy and contains three domains: self-efficacy for obtaining respite (five-items); self-efficacy

for responding to disruptive patient behaviours (five-items); and self-efficacy for controlling upsetting thoughts about caregiving (five-items). This total score responses range from one to one-hundred. The Cronbach's alpha for this scale was greater than 0.80 for each of the three domains (Steffen, et al., 2002). This scale was scored by summing each item within each domain and dividing by the number of items. The overall score was computed summing the items and dividing by 15. In the thesis sample, the Cronbach's alpha was 0.85.

3.2.5 Caregiver adaptational outcomes. Caregiver adaptational outcomes refers to the physical, emotional (morale), and social functioning of the individual. For this thesis adaptational outcomes, were investigated through 2 measures: (1) The Health Status Questionnaire (HSQ-12), and (2) The Center for Epidemiological Studies Depression Scale (CES-D); these will be further described below.

3.2.5.1 Health status questionnaire- caregiver (HSQ-12). The Health Status Questionnaire (HSQ-12) is a widely used measure of overall health (Pettit, et al., 2001). For the thesis, it is used as a measure for well-being. Item score ranges differed depending on the question. Question 1 related to general health and ranged from 1 to 5, with 1 being excellent and 5 being poor. Questions 2 – 4 relate to activities that might be done on a typical day and if health is limited to do these activities, these questions ranged from 1 to 3, with 1 being, yes, limited a lot and 3 being, no, not limited at all. Questions 5 – 7 related to the past 4 weeks and asked about their health, ability to accomplish tasks and about physical or emotion problems interfering with their normal activities. Questions 5 – 7 ranged from 1 to 5, with 1 being None at all, and 5 being extremely. Questions 9 – 12 related to how the caregiver feels and how things have been for them

during the past 4 weeks. Questions 9 – 12 ranged from 1 to 4, with 1 being all the time and 4 being rarely. Recoded scores on the HSQ-12 range between 0 and 100 (Pettit, et al., 2001), the higher the score indicates better overall health and well-being. This questionnaire includes eight domains. The eight domains include: health perception (one item, question 1); physical functioning (three items, questions, 2, 3, and 4); role limitation due to physical health problems (one item, question 5); role limitation due to emotional problems (one item, question 6); social functioning (one item, question 7); bodily pain (one item, question 8); mental health (three items, questions 9, 11, and 12); and energy (one item, question 10) (Pettit, et al., 2001, p. 1062). For scoring of the HSQ-12, the Scoring Algorithms and rules from Ware, Kosinski, and Keller (1996) were followed.

3.2.5.2 Center for epidemiological studies depression scale (CES-D). The Center for Epidemiological Studies Depression Scale (CES-D) is an instrument used for screening for depression and measuring depression symptoms (Radloff, 1977). The CES-D has been used many times and has a high internal consistency; Cronbach's alpha ranging from 0.85 – 0.90 (Radloff, 1977). There are 20-items on the scale. This scale uses a 4-point ordinal scale for items, rated from zero to three. An item score of zero means 'rarely or never' and a score of 3 means 'most or all of the time'. The summary score is a sum of scores on the 20 items. Overall summary scores can range from zero to sixty. The higher the score indicates more depressive symptoms. In the thesis sample, the Cronbach's alpha was 0.70.

3.3 Analytic Approach

Through this section the analytic approach for the thesis is presented; including: (1) data cleaning; (2) approach to missing data; (3) scoring and; (4) plan for how research questions would be answered.

Data cleaning is assessing and checking the data to make sure that it is fit for analysis (Polit & Tatano Beck, 2012). This process needs to be completed, even with secondary data analysis. This process was completed through assessing the number of cases of participants in the file ($n = 76$). Data was transferred from Excel spreadsheets into SPSS files ready for analysis. Two checks were completed; the first one was for outliers. Outliers are values that are outside of a normal distribution or greater than three standard deviations. This process was checked via constructing frequency distributions for all variables in the data set (Polit & Tatano Beck, 2012). The second check was for a wild code or a code that is not possible (Polit & Tatano Beck, 2012). For all created SPSS files, missing data were inputted with the number 599. This was checked through SPSS before analysis began by creating a frequency table to make sure all items have a value, so there are no missing variables or errors.

Missing data, as mentioned above, was coded as 599. Since most statistical procedures require a value for every item/variable, a data set with missing values cannot be fully used (Fox- Wasylyshyn, & El-Masri, 2005). Since the sample size is relatively small, deletion of cases with missing data was not used. This preserves the highest statistical power possible for this study. Missing within a scale items were imputed through mean series imputations, specifically case mean substitution. “Case mean substitution ascribes the subject’s mean score based upon the items that are present to the missing score for that subject” (Fox-Wasylyshyn, & El-Masri, 2005, p. 491). For

participants with 25 percent of items or less within a scale missing, the mean of the present items for the participant was calculated and imputed for the missing item; this follows Aday and Cornelius's (2006) recommendation that when 25 to 50 percent of values are missing the case should be excluded. Case mean substitution is appropriate for self-report measures (Fox-Wasylyshyn, & El-Masri, 2005). Also, using case mean imputations has the advantage of recognizing differences across cases by using the data provided from the case to input missing data values opposed to using data from outside cases to create a value (Fox-Wasylyshyn, & El-Masri, 2005).

Overall, mean imputations are a simple method that increases the sample size, and leaves the variables' means unaffected (Polit & Tatano Beck, 2012). The pattern of missingness and the frequency of use of mean imputation are reported.

Scoring of the data followed the instructions published with each measure. Cronbach's alpha was computed for each scale or subscale used in the thesis analyses, except for HSQ-12 because this scale measures more than one concept.

The research questions were answered through quantitative techniques. This includes multivariate analyses.

Sample description includes frequency distributions of values of categorical variables (education) and mean, standard deviation, median, and mode of continuous variables. Descriptive statistics (mean, median, mode, and dispersion) were computed for each measure scale or subscale.

The research questions were answered using linear regression analyses (described below). Any type of regression analysis requires that assumptions must be checked and reported on. The assumptions for linear regression that were checked include: (1)

existence; (2) independence; (3) linearity; (4) homoscedasticity; and (5) normal distribution (Kleinbaum, Kupper, & Muller, 1988). All assumptions were checked and assessed using IBM SPSS Statistics 20 including, histograms, scatter plots, line of best fit, mean, median, mode, Pearson correlation, Malhalanobis distance, and chi-square assessment.

Sample size must be checked to make sure that it is large enough to conduct specific types of analyses. Green (1991) states (as cited in Tabachnick & Fidell, 2007) that the number of cases is equal to or greater than 50 cases, plus eight times each independent variable that will be used in the equation (p. 123). Therefore, with a sample size of 76 the number of independent variables to be included in a complex equation is either three or four. For the current study, there were less than 76 for multivariate analysis, due to missing data between the measures. This was assessed at time of analysis.

All statistical analyses were conducted with the computer program IBM SPSS Statistics 20. A two-tailed significance level of $\alpha = 0.05$ was used for all analyses.

For the fourth research question, testing potential pathways of associations was proposed as seen in Figure 3. The mediation pathway between coping resources and appraisal was not able to be tested because the variables used to measure these concepts were not related and did not satisfy the conditions for mediation to continue.

Figure 3. Model of Associations that were proposed to be tested from the Adaptational Theoretical Model



Figure 3. Model showing the associations that were planned to be tested through using the statistical technique of regression. This would include 2 separate tests of mediation. The first mediation test explores if coping resources mediates the relationship between cultural values and well-being. The second mediation test explores if appraisal mediates the relationship between coping resources and well-being. The above model shows these associations in a pathway model.

3.3.1 Control variable. Through the regression analyses selected to answer the research questions, a control variable was used in all models. This will help to understand and sort out confounding or extraneous variables. As Polit and Tatano Beck (2012) note “research control is a critical tool for managing bias and for enhancing validity in quantitative studies” (p 179). Caregiving is a complex phenomenon; including a control variable will allow for understanding of the associations being tested.

In health research, socioeconomic status is a determinant of health. Determinants of health are factors that contribute to an individual’s overall health status; these factors influence one another (Potter, Perry, Ross-Kerr, & Wood, 2006). For the current study two variables on the demographic face sheet are determinants of health: income and education. The relationship between income and health has been that Canadians with lower incomes are more likely to die earlier, and suffer from more illnesses compared to Canadians with higher incomes (Potter, et al., 2006). Income was measured as one item with a range from 1 to 5, with 5 being over \$50,000. Limiting the upper category to over \$50,000 does not reflect the full range of incomes in this sample. Thus, income was not included as a control variable for the current study.

The relationship between education and health is interesting because education has been suggested to influence many other health determinants, including: income, physical environment, and health practices (Potter, et al., 2006). It has been suggested that individuals with higher education have increased access to health care, more job opportunities, income, and problem solving skills (Potter, et al., 2006). Education was included as a control variable for the current study. Education was measured as an item on the demographic face sheet. Education included a range from 1 to 3, with 1 meaning post high school training (this includes: graduate professional training, and standard college or university); 2 meaning high school (this includes, partial college or university and high school graduate) and 3 meaning less than high school (this includes partial high school training, junior high school and <7 years of schooling). Education is a strong determinant of health to include in the study because it includes influence from other determinants of health, which helps in interpretation. Using education as a control variable allows for the effects beyond this proxy of socioeconomic status to be controlled.

A clear link between education and caregiving has been made through the literature review. It was noted that caregiving can have an impact on the caregivers' health, and negative effects on employment, income, and family finances (Alzheimer's Association, 2012). Previous research from a review article notes that socioeconomic status and education are confounding variables in dementia caregiving research (Botsford, et al., 2011). In Pinquart and Sörensen's (2005) meta-analysis it was noted that predictors of caregiver outcomes were similar between ethnic groups except for a few factors; one included income. In the critique of the research, it was noted that not all research controlled for socioeconomic status or education and this made comparison of

results and interpretation difficult. Education should be, and was controlled for in the current study to avoid confounding effects that have been reported in caregiving literature. A clear association is noted with education and dementia caregiving, so this relationship must be accounted to avoid statistical error and help the findings be comparable to other research.

3.4 Answering the Research Questions

To answer the first research question, “**Are traditional values for family caregiving associated with caregiver stress appraisal?**” multivariate linear regression analyses were used. The multivariate linear regression method selected was hierarchical regression. This allows for the order of the variables entered to be controlled by the researcher. Education was entered in the model first as the control variable followed by the CJCS.

Corresponding to the theoretical model, caregiver stress appraisal was the dependent variable and traditional values for family caregiving, was the independent variable. Two models were created, one for each of the caregiver stress appraisal variables (MAASD-D and NPI-D):

Two models were created, including education as a control variable.

$$1. \text{ MAASD-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

$$2. \text{ NPI-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

From the models created, statistical significance of the prediction and the amount of variance explained was reported.

Another statistical technique that was used to answer the first research question is moderation. In general, a “moderation model tests whether the prediction of a dependent

variable, Y, from an independent variable, X, differs across levels of a third variable, Z” (Fairchild & MacKinnon, 2009, p. 89). The strength or direction of a relationship on the predictor and outcome variables is affected by a moderator variable (Fairchild & MacKinnon, 2009). A moderator can affect a relationship through enhancing, reducing, or changing the relationship influence (Fairchild & MacKinnon, 2009). In this case, traditional values for family caregiving are hypothesized to affect how the caregiver appraises caregiving stressors. To test for moderation two separate tests were conducted to explore the two caregiver stress appraisal variables (MAASD and NPI):

$$3. \text{NPI-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{NPI Severity} + \beta_3 \text{CJCS} + (\beta_4 \text{NPISeverity} \times \text{CJCS}) + \varepsilon$$

$$4. \text{MAASD-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{MAASD Function Ability} + \beta_3 \text{CJCS} + (\beta_4 \text{MAASDFunction} \times \text{CJCS}) + \varepsilon$$

To answer the second research question, “**Are traditional values for family caregiving associated with caregiver coping resources (social support and self-efficacy)?**” multivariate linear regression analyses were used. Again, for multivariate linear regression, hierarchical regression method was selected, including education as the control variable first entered in the model.

Corresponding to the theoretical model, caregiving coping resources (social support and self-efficacy) were the dependent variables and traditional values for family caregiving was the independent variable. Two models were created, one for each of the coping resources variables (MSPSS and the Revised Scale for Caregiving Self-Efficacy):

$$5. \text{MSPSS} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

$$6. \text{Revised Scale for Caregiving Self-Efficacy} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

To answer the third research question, **“Are traditional values for family caregiving associated with caregiver well-being?”** multivariate linear regression analyses were completed. Hierarchical regression was applied, including education as the first entered variable as the control.

Corresponding to the theoretical model, adaptational outcome or well-being was the dependent variable and traditional values for family caregiving, was the independent variable. Two models were created, one for each of the adaptational outcome variables (CES-D and HSQ-12):

$$7. \text{ CES-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

$$8. \text{ HSQ-12} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \varepsilon$$

To answer the final and fourth research question, **“Do caregiver coping resources and appraisal mediate the relationship between traditional values for family caregiving and caregiver well-being?”** multivariate regression analyses were used. This was conducted through hierarchical regression analyses. This tested the associations that can be visualized in Figure 2.

A mediator variable is an “indirect effect that represents at least part of the chain of events leading to changes in the dependent variable” (Tabachnick & Fidell, 2007, p. 159). A variable must meet three conditions in order to be judged as a mediator: (1) levels of the independent variable (traditional values for caregiving) have to significantly account for variations in the mediator variable (either MSPSS or Revised Scale for Caregiving Self-Efficacy); (2) levels of the mediator (either MSPSS or Revised Scale for Caregiving Self-Efficacy) must significantly account for variation in the dependent variable (CES-D or HSQ-12); and (3) if path from the previous two relationships are

controlled for, a previously significant relationship between the independent and dependent variable is no longer significant. The strongest demonstration of this would be a value of zero; however a more realistic value would be for it to be decreased, since there could be many mediating factors (Baron & Kenny, 1986, p. 1176).

To test for mediation there are three steps that need to be completed. When testing for a mediator, three models need to be created (Baron & Kenny, 1986). The models for regression equations include: (1) regression model with the mediator on the independent variable; (2) regression model with dependent variable on the independent variable; and (3) regression model of the independent variable and mediator variable on the dependent variable (Baron & Kenny, 1986, p. 1177).

Figure 4. Model of Mediation

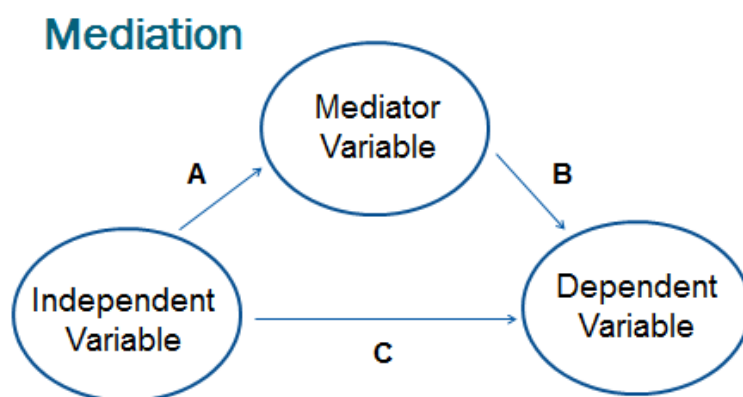


Figure 4. Model showing mediation which, tries to identify and explain the process for an observed relationship between an independent variable and a dependent variable through including a third explanatory variable, known as a mediator. For this thesis the independent variable was traditional values for family caregiving and the dependent variables were the caregiver well-being variables. The mediators were coping resources (social support and self-efficacy).

The analytic plan was that this analysis would be conducted if findings from analyses for research questions 2 and 3 indicated that the first 2 conditions of mediation

were met. The first two conditions were met for the well-being caregiver outcome (HSQ-12) but not for the depression caregiver outcome (CES-D). The third step of the mediation analysis for caregiver well-being was conducted through multiple linear regressions with education included as a control variable, shown below:

$$9. \text{HSQ-12} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \beta_3 \text{MSPSS} + \varepsilon$$

$$10. \text{HSQ-12} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{CJCS} + \beta_3 \text{Revised Scale for Caregiving Self-Efficacy} + \varepsilon$$

The betas for CJCS from these equations were compared to the beta for CJCS in equation 8 to test for mediation. Assessing the beta weight and changes in statistical significance is known as the Baron and Kenny method to assess for mediation (Kenny, 2013; Biesanz, Falk, and Salavei, 2010). This was done. Also, to supplement the Baron and Kenny method, a second method of assessing mediation known as the partial posterior (PP) method was conducted. The partial posterior (PP) method was shown by Biesanz, et al., (2010), to be as good as or superior to other methods of testing the significance of mediation. The partial posterior (PP) *p* value for mediation was calculated using, the indirect effect *p*-value calculator (Falk, 2012). Instructions for using the indirect effect *p*-value were followed. This includes three steps: (1) enter the *t* statistic and degrees of freedom from path a of the mediation model; (2) enter the *t* statistic and degrees of freedom from path b of the mediation model and; (3) choose the level of computational accuracy, ‘good’ was selected for the thesis. ‘Good’ indicates for inferences used at the $\alpha = 0.05$ level (Falk, 2012).

A second mediation relationship was proposed, but analyses to test it were not conducted. This mediation analysis was going to investigate if relationships between

coping resources and well-being were mediated by appraisal. This was part of a larger chain of effect that was going to be tested (See Figure 3). The first condition of mediation, a relationship between coping resources and well-being was not met, so the mediation model was not tested.

To test the theoretical model two multivariate linear regression analyses were completed. Hierarchical regression was applied, including education as the first entered variable as the control. These analyses investigated the outcome measure of well-being (HSQ-12 and CES-D) looking at the full model and individual predictor levels. Models for this analysis can be viewed below:

$$11. \text{HSQ-12} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{NPI-D} + \beta_3 \text{MAAS-D} + \beta_4 \text{CJCS} + \beta_5 \text{MSPSS} + \beta_6 \text{Revised Scale for Caregiver Self-Efficacy} + \varepsilon$$

$$12. \text{CES-D} = \beta_0 + \beta_1 \text{Education} + \beta_2 \text{NPI-D} + \beta_3 \text{MAAS-D} + \beta_4 \text{CJCS} + \beta_5 \text{MSPSS} + \beta_6 \text{Revised Scale for Caregiver Self-Efficacy} + \varepsilon$$

The addition of a control variable means that the guide from Tabachnick and Fidell (2007) for sample size and number of variables was not used for these final models and does bring the question of statistical power into question. However, this is exploratory research.

3.5 Recognizing and Limiting Bias

Bias can be defined “as any influence that distorts the results of a study and undermines validity” (Polit & Tatano Beck, 2012, p. 720). Bias has three main sources taken into consideration: (1) sample or sampling method; (2) measurement; and (3) analyses.

For the present thesis, a convenience sample was used. Convenience sampling can have a great amount of bias (Polit & Tatano Beck, 2012). In order to minimize potential bias, the original researchers recruited from several service agencies. This results in what Sackett, (1979) would call membership bias, where the sample includes caregivers who are receiving some services, not caregivers who are not part of the service agencies that were recruited from. Most of the previous researches in this field of study have also used convenience sampling methods.

As with primary data secondary data is not exempt to data organization, cleaning, assessing, and checking the data before conducting statistical analyses (Bibb, 2007). When there are missing data either at the item or variable level, this is a problem because lost data can lead to the loss of statistical power and bias in estimates analysis (Fox-Wasylyshyn, & El-Masri, 2005). Earlier, case mean imputation was mentioned as the selected method for missing data. However, it is important to note that mean imputations underestimates variance, but does not change the mean (Polit & Tatano Beck, 2012). Underestimating variance increases chances of Type I error.

Measurement can be assessed through reliability and validity. Each of the measures included in the thesis have been shown to be reliable, as described above in the measures section, and have been used multiple times in different research samples. Data were collected via trained graduate and senior undergraduate health students, limiting bias (Marziali, et al., 2010).

Analyses are another area for bias to enter research. Through this thesis analytical bias was avoided through using appropriate statistical analyses to answer the research questions. Meeting the frequently used requirements for significance which, as Polit and

Tatano Beck (2012) indicate is a significance level or alpha (α) of 0.05, ensures that my results are comparable to other research and allows for balance to be maintained between Type I and Type II error. When conducting multivariate regression analyses, all assumptions required were met to ensure the statistical technique was appropriate for use. Sample size was considered for bias and statistical approaches. Sample size recommendations were followed to ensure that there are not too many variables in an equation, to limit bias (Tabachnick & Fidell, 2007).

It is important to note that when small or modest relationships are being investigated, a large sample is needed to avoid a Type II error (Polit & Tatano Beck, 2012). Having a small sample, such as the one in the current study, limits the ability to find and interpret modest relationships.

Effect size will be reported to help interpreting findings. Effect size refers to the “magnitude of the relationship between the research variables” (Polit & Tatano Beck, 2012, p. 423). Pearson correlation can be used; R^2 was interpreted for the current study. Effect size was explored because “statistical significance testing assesses the reliability of the association between the independent variable and the dependent variable. Effect size measures how much association there is” (Tabachnick & Fidell, 2007, p. 54). Effect size aides in interpreting associations, even when they are not statistically significant.

Conducting multiple statistical tests on the data set and using the $\alpha = 0.05$ increases Type I error. The Bonferroni correction would make the significance testing more rigorous (Norman & Streiner, 1994). However, since this is exploratory research, with a small sample size and small effect size, this correction was not used because it

would have a high chance of eliminating any positive result that could be further researched in the future.

Chapter 4: Results

Through this chapter the thesis results are presented. The results section will include information on: (1) the characteristics of the sample; (2) data cleaning; and (3) findings from answering the research questions.

4.1 Sample Characteristics

Sample characteristics are described and can be visualized in Table 2. Overall, 55 (72.4%) of caregiver respondents were female. The mean age of the caregivers was 72.5 years ($SD = 15.1$ years). Thirty-three (43.4%) of the caregivers were a spouse or partner of the PWD; 31 (40.8% of the caregivers were a child of the PWD; and 9 (11.8%) of the caregivers were another relative. Most of the caregivers had children of their own ($n = 60$, 78.9%). The mean length of time the caregivers had been providing care was 6.0 years ($SD = 4.7$ years). The mean approximate hours a day spent on caregiving was 13.4 hours ($SD = 8.8$ hours).

Most of the respondents' country of origin was North America, 47 (61.8%), followed by Western Europe, 14 (18.4%); Eastern Europe, 8 (10.5%); South America, 2 (2.6%); Asia, 2 (2.6%); and Israel, 1 (1.3%). Of those who immigrated, 22 (28.9%) immigrated between 1950 and 1970.

Seventy-four caregivers provided information about their ethnic background. Of these, the most frequently reported ethnic background was Western European, 37 (48.7%). Religious affiliation of the 75 respondents who answered this question was most frequently reported as Protestant ($n = 24$, 31.6%).

Over half of the participants have completed post high school education ($n = 42$, 55.3%). Twenty (26.3%) of the participants completed high school and 11 (14.5%) of the participants completed less than high school; results can be viewed in Table 3.

The characteristics of the care recipients will be described. A total of 38 (50.0%) of the care recipients were male. The mean age of the care recipients was 71.7 years ($SD = 14.8$ years). The Mini Mental State Examination score was available for 33 (43.4%) and the mean score was 13.1 ($SD = 9.5$). Scores ranging from 13-20 on the MMSE suggest moderate dementia according to the Alzheimer's Association (2013). Care recipient data can be visualized in Table 4.

Care recipient behavioural symptoms and functional abilities as reported by caregivers were an average severity of 11.12 ($SD = 6.48$) on the NPI measure, showing mild severity and 1.76 ($SD = 0.63$) on the MAASD, showing mild to moderate functional abilities. More detailed information can be found from Table 1, which also includes descriptive statistics for all scale measurements used for analysis.

4.2 Data Screening and Cleaning

The first data screening and cleaning activity that took place was assessing for missing cases and patterns, Table 5 shows the number of cases or items missing by measurement and includes the participant identification number (ID). As can be visualized from Table 5 there is no pattern to the missingness. As previously described in Chapter 3, those with 25% or less of the items missing were included in the study. The cases that are highlighted in yellow in Table 5 indicate the cases that were omitted in analysis. No cases were removed from CJCS, NPI, MSPSS, and HSQ-12 due to missing data. For the MAASD scale, one participant was omitted from the analysis due to missing

3 of the 5 domains. Participants with missing over 25% for only 1 domain were included in the analysis, due to this being exploratory research. One participant was removed from the CES-D due to missing data. Nine participants were removed from the Revised Scale for Caregiver Self-Efficacy due to missing data. This allowed for statistical power to be persevered for this portion of the theoretical model to be tested. The MAASD scoring was adjusted for these five cases, with an adjusted denominator (due to 1 domain missing). Other included scales followed the guidelines for scoring that were previously discussed, and followed the guideline for 25% or more of missing data for case removal.

Detailed information about each scale measurement used in analysis can be viewed in Table 1, which will include, mean, median, mode, dispersion (standard deviation), minimum value, maximum value, and Cronbach's alpha where appropriate.

Next the assumptions previously mentioned in chapter three were checked against all included scales. The assumptions checked included: (1) existence; (2) independence; (3) linearity; (4) homoscedasticity; and (5) normal distribution (Kleinbaum, Kupper, & Muller, 1988).

The assessment for possible univariate outliers was completed first. The standard deviation along with the mean for each scale was used to calculate what possible points would be outliers. It is noted that the CJCS, NPI, CES-D, HSQ-12, and the Revised Scale for Caregiver Self-Efficacy did not have any univariate outliers. The MSPSS had one univariate outlier of participant 17, being a value of 52. The value of 52 was changed to be 50, which is within three standard deviations of the mean, to eliminate this univariate outlier. Now the MSPSS does not have any univariate outliers.

The MAASD Distress Score had fourteen outliers, each with a value of 0; this included participants, 15, 25, 28, 32, 33, 34, 36, 37, 142, 143, 145, 154, 155, and 160. These remain unchanged because 0 indicates no distress and does not conceptually make sense to change these values to 1 because this would indicate that the caregivers do have distress, when they have reported that they do not; data analysis will proceed. All other assumptions for regression were met.

4.3 Answering the Research Questions

4.3.1 Research question one. The first research question asked: Are traditional values for family caregiving associated with caregiver stress appraisal? To answer this question, two hierarchical multiple linear regression models were run. These statistical analyses were investigating the amount of variance that traditional values for caregiving influenced above and beyond education for the two distress measures, the MAASD-D, and the NPI-D. Both models were non-significant [MAASD-D, $R^2 = 0.02$, $F(1, 70)$, $p = 0.45$ and NPI-D, $R^2 = 0.01$, $F(1, 70)$, $p = 0.70$]. Detailed results can be viewed in Tables 6 and 7.

A moderation analysis was also run investigating the two measures for distress. For prediction of NPI distress, the regression coefficient for the NPI severity by CJCS regression term was [$\beta = 0.003$, $t = 0.05$, $p = 0.96$]. There was not a statistically significant interaction between NPI severity and CJCS. The regression coefficient for MAASD function by CJCS interaction term was [$\beta = -4.08$, $t = -1.5$, $p = 0.14$]. There was not a statistically significant interaction between MAASD function and CJCS. Detailed results can be viewed in Tables 8 and 9.

4.3.2 Research question two. The second research question asked: Are traditional values for family caregiving associated with caregiver coping resources (perceived social support and self-efficacy)? To answer this question, two hierarchical multiple linear regression models were run. These statistical analyses were investigating the amount of variance that traditional values for caregiving influenced above and beyond education for two different measures of coping resources, social support (MSPSS) and self-efficacy (Revised Scale for Caregiver Self-Efficacy). In both models, the CJCS explained significant variance after controlling for the effect of education. Detailed results can be viewed in Tables 10 and 11. The full model for MSPSS approached significance [$R^2 = 0.08$, $F(1, 70)$, $p = 0.06$]. CJCS was a significant predictor for MSPSS [R^2 change, 0.07, $F(1,70)$, $p = 0.02$; $\beta = 0.26$, $t = 2.30$, $p = 0.02$].

The full model for the Revised Scale for Caregiver Self-Efficacy was significant, [$R^2 = 0.20$, $F(1, 62)$, $p = 0.001$]. The significant predictor for this model was the CJCS [$\beta = -0.42$, $t = -3.70$, $p = 0.0001$].

4.3.3 Research question three. The third research questions asked: Are traditional values for family caregiving associated with caregiver well-being? To answer this question, two hierarchical multiple linear regression models were conducted. These statistical analyses were investigating the amount of variance that traditional values for caregiving influenced above and beyond education for two different measures of well-being; including the HSQ-12, and the CES-D. Through these analyses a significant model was found for the prediction of HSQ-12, and a non-significant model for CES-D; detailed results can be viewed in Tables 12 and 13. The full model for HSQ-12 was significant [R^2

= 0.09, $F(1, 70)$, $p = 0.04$]. There was a trend towards significance for the CJCS [$\beta = 0.22$, $t = 1.95$, $p = 0.06$].

The full model for CES-D was non-significant [$R^2 = 0.02$, $F(1, 69)$, $p = 0.56$] and CJCS was not a significant predictor.

4.3.4 Research question four. The fourth research question asked: Do caregiver coping resources and appraisal mediate the relationship between traditional values for family caregiving and caregiver well-being? This question involves eight sub-questions, with the combination of the four mediator variables (MSPSS, Revised Scale for Caregiver Self-Efficacy, NPI-D, and MAASD-D) and the two caregiver outcome variables (CES-D and HSQ-12):

- a. Does social support mediate the relationship between traditional values for family caregiving and caregiver well-being?
- b. Does caregiver self-efficacy mediate the relationship between traditional values for family caregiving and caregiver well-being?
- c. Does distress about care recipient behaviour mediate the relationship between coping resources and well-being?
- d. Does distress about care recipient functioning mediate the relationship between coping resources and well-being?
- e. Does social support mediate the relationship between traditional values for family caregiving and caregiver depressive symptoms?
- f. Does caregiver self-efficacy mediate the relationship between traditional values for family caregiving and caregiver depressive symptoms?

- g. Does distress about care recipient behaviour mediate the relationship between coping resources and caregiver depressive symptoms?
- h. Does distress about care recipient functioning mediate the relationship between coping resources and caregiver depressive symptoms?

Results for each of these questions are presented in turn. When investigating coping resources as a mediator variable, it was only possible to test the mediation relationship for HSQ-12 as the outcome variable (questions a – d). The CES-D did not meet the criteria for mediation. From the analysis conducted in research question three, it was found that the CJCS was not significantly related to the outcome CES-D, which is one of the conditions needed in order for mediation to proceed.

Evidence from each of the mediation paths is presented. Looking at the relationship investigated between the CJCS and coping resources [MSPSS and Revised Scale for Caregiver Self-Efficacy]; it was found that the CJCS was a significant predictor of self-efficacy. The CJCS approached being a significant predictor of social support. This met the first condition of mediation, for exploring coping resources as a potential mediator variable. Specific results regarding CJCS and coping resources can be located in research question two, models three and four. Next it was found that coping resources [MSPSS and Revised Scale for Caregiver Self-Efficacy] were significant predictors of well-being [HSQ-12].

The mediation pathway that is being tested is if coping resources mediate the pathway between traditional values for caregiving and well-being. Two models were created, one for each of the coping resources measures. The first model explored the MSPSS as a mediator of the relationship between CJCS and HSQ-12. Both steps in the

hierarchical regression yielded statistically significant models. In the first step education as a control and CJCS were entered [$R^2 = 0.09$, $F(2, 70)$, $p = 0.04$]. In the second step education, CJCS, and MSPSS were entered [$R^2 = 0.12$, $F(1, 69)$, $p = 0.03$]. The beta weight and significance levels were reduced for the CJCS from $\beta = 0.22$, $p = 0.06$ in step 1 to $\beta = 0.17$, $p = 0.14$ in step 2. This supports the Baron and Kenny method of assessing a decrease in the beta to know when mediation has occurred. The partial posterior (PP) method was also conducted for this mediation test and revealed a significant result $p = 0.05$, also indicating that mediation has occurred. Detailed results can be viewed from Table 14.

The second mediation model tested whether coping resources mediates the relationship between the CJCS and HSQ-12, and the mediator variable used was the Revised Scale for Caregiver Self-Efficacy. Both steps in the hierarchical regression yielded statistically significant results. In the first step education as a control and CJCS were entered [$R^2 = 0.13$, $F(2, 62)$, $p = 0.01$]. In the second step education, CJCS, and the Revised Scale for Caregiver Self-Efficacy were entered [$R^2 = 0.17$, $F(1, 61)$, $p = 0.009$]. The beta weight and significance levels were reduced for the CJCS from $\beta = 0.30$, $p = 0.02$ in step 1 to $\beta = 0.20$, $p = 0.13$ in step 2. This supports the Baron and Kenny method for assessing a reduction in the beta weight and significance, indicating that mediation has occurred. The partial posterior (PP) method was also conducted for this mediation test and revealed a significant result $p = 0.01$, also indicating that mediation has occurred. Detailed results can be viewed from Table 15.

The last set of analyses that were computed to answer the fourth research question included two multiple linear regressions to test the combined and individual effects of

characteristics of the caregiver, appraisal and caregiver coping resources directly to adaptational outcomes (HSQ-12 and CES-D). Education was included as a control variable in both models.

In the first model investigating the combined and individual effect of prediction for the HSQ-12 as the outcome variable; the full model was significant [$R^2 = 0.19$, $F(5, 58)$, $p = 0.05$]. The only individual predictor that was significant in the model was education [$\beta = 0.24$, $t = 2.0$, $p = 0.05$]. None of the other included measures included in the model approached significance. Detailed results can be viewed from Table 16.

In the second model investigating the combined and individual effect of prediction for the CES-D as the outcome variable; the full model was significant [$R^2 = 0.32$, $F(5, 58)$, $p = 0.001$]. The only individual predictor that was significant in the model was NPI-D [$\beta = 0.28$, $t = 2.05$, $p = 0.05$]. None of the other included measures included in the model approached significance. Detailed results can be viewed from Table 17.

Table 1. Scale Measurements: Descriptive Statistics

Scale Measurement	Mean (<i>SD</i>)	Median	Mode	Min. Value	Max. Value	Cronbach's alpha
CJCS	17.46 (5.80)	17.0	10 ^a	10	33	0.80
NPI Distress	12.71 (9.60)	11.0	4 ^a	0	42	0.81
MAASD Distress	1.01 (0.60)	0.98	1	0	3	0.91
MSPSS	24.07 (8.64)	24.5	12	12	50	0.89
Revised Scale for Caregiver Self-Efficacy	75.48 (16.77)	75.33	60 ^a	25	100	0.85
CES-D	17.72 (7.2)	15.0	14	4	39	0.70
HSQ-12	44.26 (8.76)	43.25	43	18	63	-
NPI Severity	11.12 (6.48)	10.5	11	0	28	-
MAASD Function	1.76 (0.63)	1.8	1	1	3	-

^a multiple modes exist

Table 2. Caregiver Characteristics

Caregiver Characteristics	Mean (<i>SD</i>)	n (%)
Age (years)	72.5 (15.1)	
Gender		
Male		19 (25.0)
Female		55 (72.4)
Relationship		
Spouse or Partner		33 (43.4)
Child		31 (40.8)
Relative		9 (11.8)
Length of Caregiving (years)	6.0 (4.7)	
Approximate Hours a Day Spent Caregiving	13.4 (8.8)	
Country of Origin		
North America		47 (61.8)
South America		2 (2.6)
Eastern Europe		8 (10.5)
Western Europe		14 (18.4)
Israel		1 (1.3)
Asia		2 (2.6)
Immigrated to Canada		30 (40.0)
Date of Immigration to Canada		
1931 to 1950		1 (1.3)
1951 to 1970		22 (28.9)
1971 to 1990		6 (7.9)
>1990		1 (1.3)
Ethnic Background		
Jewish (Israeli)		6 (7.9)
Eastern European		10 (13.2)
Western European		37 (48.7)
Canadian		14 (18.4)
Other (East Indian, Pakistani, Philipino)		7 (9.2)
Religious Affiliation		
No Religion		11 (14.5)
Catholic		22 (28.9)
Protestant		24 (31.6)
Jewish		16 (21.1)
Muslim		2 (2.6)
If Caregivers have Children		
Yes		60 (78.9)

Table 3. Level of Education Achieved for Caregivers

Level of Education Achieved for Caregivers	n (%)
Post High School Education	42 (55.3)
High School Graduate	20 (26.3)
Less than High School	11 (14.5)

Table 4. Care Recipient Characteristics

Care Recipient Characteristic	Mean (<i>SD</i>)	n (%)
Age (years)	71.7 (14.8)	
Gender		
Male		38 (50.0)
Female		35 (46.1)
Mini Mental State Examination (MMSE)		
completed	13.1 (9.5)	
MMSE Score 27-30 (Normal)		2 (6.1)
MMSE Score 10-26 (Mild to Moderate AD)		18 (54.5)
MMSE Score less than 10 (Severe AD)		13 (39.4)

Table 5. Missing Data at the Item and Case Level by Measure

Measurement Scale	Number of Missing items n (%)	Participant ID Numbers
CJCS	0	N/A
MAASD- ADL	1 (7.1)	24, 25, 32, 36, 46, 53
	14 (100.0)	135
MAASD- Mobility	1 (10.0)	3, 4, 9, 11, 19, 26, 28, 33, 37, 41, 42, 43, 44, 53, 57, 145, 154, 156, 157
	2 (20.0)	8, 16, 46, 47
	3 (30.0)	15
	4 (40.0)	23
	10 (100.0)	135
MAASD- Communication	6 (100.0)	135
MAASD- IADL	1 (6.3)	47, 158
	2 (12.5)	15
	3 (18.8)	59
	5 (31.3)	58
	16 (100.0)	8
MAASD- Mental Functions	8 (80.0)	158
NPI	1 (8.3)	32, 33, 157
	2 (16.7)	34
MSPSS	1 (8.3)	18, 58, 59
Revised Scale for Caregiver Self-Efficacy	1 (5.3)	8, 33, 57, 59, 159
	2 (10.5)	26, 28, 132
	3 (21.1)	114, 158
	4 (27.0)	6
	5 (33.0)	34, 41, 44, 47
	7 (47.0)	46
	9 (60.0)	35
	19 (100.0)	12, 25
HSQ-12	1 (8.3)	29, 53, 158
CES-D	1 (5.0)	6, 30, 126
	2 (10.0)	10, 19
	20 (100.0)	25

Table 6. Model 1: CJCS Predicting MAASD-D Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.12	0.09	0.02		0.30	1, 71	0.30
Step 2							
Education	0.13	0.09					
CJCS	0.09	0.01	0.02	0.007	0.47	1, 70	0.45

* β Sig. < .05

Table 7. Model 2: CJCS Predicting NPI-D Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	-0.06	1.52	0.004		0.59	1, 71	0.59
Step 2							
Education	-0.06	1.52					
CJCS	0.08	0.20	0.01	0.006	0.52	1, 70	0.70

* β Sig. < .05

Table 8. Moderation Test: Investigating the Hypothesized Effect of Caregiver Appraisals of Stressors through the NPI

Variable	β	Standard Error	R^2	$R^2\Delta$	F	df	Sig.
Education	0.05	0.78					0.39
CJCS	0.04	0.10					0.47
NPI-Severity	0.87	0.09					0.0001
CJCS by NPI-Severity	0.003	0.02					0.96
Model			0.76	-	54.42	4, 68	0.0001

* β Sig. < .05

Table 9. Moderation Test: Investigating the Hypothesized Effect of Caregiver Appraisals of Stressors through the MAASD

Variable	β	Standard Error	R^2	$R^2\Delta$	F	df	Sig.
Education	0.02	0.09					0.89
CJCS	-4.06	0.28					0.14
MAASD-Function	0.40	0.11					0.001
CJCS by MAASD-Function	-4.08	0.02					0.14
Model			0.17	-	3.59	4, 68	0.01

* β Sig. < .05

Table 10. Model 5: CJCS Predicting MSPSS, Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.09	1.38	0.01		0.44	1, 71	0.44
Step 2							
Education	0.10	1.34					
CJCS	0.26*	0.17	0.08	0.07	0.02	1, 70	0.06

* β Sig. < .05

Table 11. Model 6: CJCS Predicting the Revised Scale for Caregiver Self-Efficacy, Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.14	2.87	0.02		0.27	1, 63	0.27
Step 2							
Education	0.12	2.62					
CJCS	-0.42*	0.34	0.20	0.18	0.001	1, 62	0.001

* β Sig. < .05

Table 12. Model 7: CJCS Predicting HSQ-12, Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.19	1.37	0.04		0.10	1, 71	0.10
Step 2							
Education	0.20	1.35					
CJCS	0.22	0.17	0.09	0.05	0.06	1, 70	0.04

* β Sig. < .05

Table 13. Model 8: CJCS Predicting CES-D, Controlling for Education

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	-0.13	1.15	0.02		0.28	1, 70	0.28
Step 2							
Education	-0.13	1.16					
CJCS	-0.01	0.15	0.02	0.00	0.91	1, 69	0.56

* β Sig. < .05

Table 14. Testing Mediation: Coping Resources as a Mediator through HSQ-12 with MSPSS and CJCS

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.20	1.35					
CJCS	0.22	0.17	0.09		0.04	2, 70	0.04
Step 2							
Education	0.18	1.34					
CJCS	0.17	0.18					
MSPSS	0.19	0.12	0.12	0.03	0.12	1, 69	0.03

* β Sig. < .05

Table 15. Testing Mediation: Coping Resources as a mediator through HSQ-12 with Revised Scale for Caregiver Self-Efficacy and CJCS

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.21	1.47					
CJCS	0.30*	0.19	0.13		0.01	2, 62	0.01
Step 2							
Education	0.24*	1.46					
CJCS	0.20	0.20					
Revised Scale for Caregiver Self-Efficacy	-0.23	0.07	0.17	0.04	0.08	1, 61	0.009

* β Sig. < .05

Table 16. Testing Individual and Combined Effect of Theoretical Model through Appraisal, Traditional Values for Caregiving, and Coping Resources and its Relationship to Well-being (HSQ-12)

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	0.2	1.53	0.04		0.11	1, 63	0.11
Step 2							
Education	0.24*	1.52					
NPI-D	-0.1	0.15					
MAASD-D	-0.06	2.21					
CJCS	0.18	0.21					
MSPSS	0.12	0.14					
Revised Scale for Caregiver Self-Efficacy	-0.25	-1.65	0.19	0.15	0.07	5, 58	0.05

* β Sig. < .05

Table 17. Testing Individual and Combined Effect of Theoretical Model through Appraisal, Traditional Values for Caregiving, and Coping Resources and its Relationship to Well-being (CES-D)

Variable	β	Standard Error	R^2	$R^2\Delta$	Sig. $F\Delta$	df	Sig.
Step 1							
Education	-0.08	-0.63	0.01		0.53	1, 63	0.53
Step 2							
Education	-0.08	0.1					
NPI-D	0.28*	0.1					
MAASD-D	0.13	1.54					
CJCS	-0.13	0.15					
MSPSS	0.17	0.1					
Revised Scale for Caregiver Self-Efficacy	-0.21	0.06	0.32	0.31	0.0001	5, 58	0.001

* β Sig. < .05

Chapter 5: Discussion

Through this chapter the thesis findings are discussed. The discussion section includes: (1) a discussion of each research question; (2) study limitations; and (3) concluding remarks for future research.

5.1 Sample Characteristics

Sample characteristics in regards to the research variables are discussed. The CJCS is presented first. The sample ranged from 10 – 33. The full range of the scale is 10 – 40. The data represents a skewed distribution, with limited range. There were not many caregivers of PWD at the high end of the CJCS scale, while there were many caregivers scoring in the lower end of the scale. The mean score on the CJCS was found to be 17.5 ($SD = 5.8$). The results are in contrast to previous research from Dilworth-Anderson, et al., (2004), in their sample a full scale range from 10 – 40 was obtained. Brummett, et al., (2012) reported a mean score of 35 ($SD = 6.2$) for African American caregivers and 32.4 ($SD = 6.1$) for White caregivers; these mean scores indicate samples had higher in traditional values for caregiving compared to the current sample.

The mean age of the caregivers for this sample was 72.5 years. This was significantly older than Dilworth-Anderson, et al., (2004) who reported their mean caregiver age as, 55.9 years and Brummett, et al., (2012) who reported their mean caregiver ages to be 52.3 years for African American caregivers and 53.9 years for White caregivers.

The sample had a majority of the caregivers of PWD as female, 72.4%, which was similar to Dilworth-Anderson, et al., (2004) who reported 79% of their caregiving sample was female.

The mean for the CES-D for the sample of caregivers of PWD was 17.7 ($SD = 7.2$). This indicates that approximately half of the sample has mild depressive symptomology, since the cut off value for depression is 16 or greater. This is a similar finding to Brummett, et al., (2012) who found that White caregivers had CES-D scores in the 16 or greater range, but that African American caregiver scores were less than 16 and did not meet the clinical cut off.

5.1.1 Research question one discussion. Research question one asked, “Are traditional values for family caregiving associated with caregiver stress appraisal?” The adaptational theoretical model would propose that characteristics of the caregiver [traditional values for caregiving, CJCS] would be associated with how the caregiver appraises stressors. Neither of the two models that tested associations between the CJCS and caregiver stress appraisal (MAASD-D and NPI-D), were significant or approached significance, indicating with this sample that after controlling for the effect of caregiver education, traditional values for family caregiving were not associated with stress appraisal. A possible interpretation of this finding could be a Type II error, due to low statistical power.

The proposed association between CJCS and appraisal was also investigated through two moderation analyses. A moderator can affect a relationship through enhancing, reducing, or changing the relationship influence (Fairchild & MacKinnon, 2009). This test resulted in non-significant findings, meaning that in this case traditional values for family caregiving did not affect how the caregiver appraises caregiving stressors. This was an unexpected result based on the adaptational theoretical model, which would propose that higher levels of traditional values for caregiving would be

associated with lower burden appraisals. From the review of the literature findings about race, ethnicity, or culture with burden appraisal were mixed (Aranda & Knight, 1997; Botsford, et al., 2011; Connell & Gibson, 1997; Daker-White, et al., 2002; Dilworth-Anderson, et al., 2002). Specifically Knight and Sayegh (2010) found that familism, a component of the CJCS did not have an effect on burden appraisals made by caregivers of PWD, thus this finding is similar to Knight and Sayegh (2010). A possible explanation for not finding a significant amount of variance accounted for by the CJCS is that for the current thesis study there was no separation of the sample into sub-groups, as much of the research before has been done. Potentially, this also could indicate that traditional values for caregiving and burden appraisal are not associated concepts.

5.1.2 Research question two discussion. Research question two asked ‘Are traditional values for family caregiving associated with caregiver coping resources (social support and self-efficacy)?’ The adaptational theoretical model would propose that characteristics of the caregiver [traditional values for caregiving, CJCS] would be associated with caregiver coping resources. It is suggested that having higher amounts of social support or higher levels of self-efficacy would be related to having higher traditional values for caregiving.

Firstly, the relationship between social support and traditional values for caregiving will be examined. From the available research in the field there are conflicting findings about whether minority caregivers have more extended networks compared to White caregivers, some research indicated that they do (Dilworth-Anderson, et al., 2002; Javenic & Connell, 2001; Milne & Chryssanthopoulou, 2005; Nápoles, et al., 2010)

whereas Pinquart & Sörensen (2005) indicate that ethnic minority caregiver may not have more extended networks.

In a primary research study, caregivers were categorized as traditional ideologies for caregiving and non-traditional ideologies for caregiving (Lawrence, et al., 2008). This study reported that caregivers with non-traditional ideologies were more demanding of services and felt their needs were not met. This could be similar to perceived level of support. Shurgot and Knight (2005) found a commonality between African American and White caregivers was that they both were prone to name other family members as emotional main helpers. Family support is one of the components on the MSPSS. This also reinforces that splitting caregivers into sub-groups based on race, ethnicity, or culture is not necessary because the relationships are the same.

This study found that after controlling for the effects of education, there was a trend for an association between traditional values for caregiving and the caregivers perceived level of support ($p = 0.06$). Higher levels of CJCS were associated with higher perceived levels of social support [MSPSS]. For every unit increase in the CJCS a 0.39 unit increase in MSPSS is predicted when controlling for education. This finding supports the adaptational theoretical model. It is important to note here that some other research was investigating formal social support, and the MSPSS is a measure investigating the participants perceived level of social support from family, friends, and significant other. Thus, the MSPSS is a measure that only pertains to informal support from friends, family, and significant other and does not include any information about formal services that the caregivers might be receiving. It is also important to note that all caregivers included in this study are receiving a formal support service. In the full model

when CJCS was included and education was controlled for, there was a significant F change ($p = 0.02$) and the CJCS accounted for 7% of the variance ($R^2\Delta = 0.07$) in perceived social support.

The next model investigated was the relationship between self-efficacy and traditional values for caregiving. What the review of the literature found were discrepant findings. Specifically it was found that caregivers in the Asian ethnic group had a higher self-efficacy compared to other ethnic groups (Sun, et al., 2012). The caregiver's kin relationship was also associated with self-efficacy; indicating lower self-efficacy for spouses (Pinquart & Sörensen, 2005). This review was unable to find research about self-efficacy and traditional values for family caregiving, leading to a new finding. This study found that, controlling for the effect of education, self-efficacy and traditional values for caregiving produced a significant model, with a negative association. The model indicated that for every unit increase in the CJCS that 1.24 unit decrease in Revised Scale for Caregiver Self-Efficacy is predicted when controlling for education. Overall the model indicated that the higher levels of traditional values for family caregiver were associated with lower levels of self-efficacy. This finding supports the theoretical model because there does seem to be an association between traditional values for caregiving and self-efficacy; however the direction of the proposed relationship was not supported. Potential reasons for this finding could be because this sample was not split into sub-groups. The current sample had 43.4% report being the care recipient's spouse or partner, which could influence the findings; since lower self-efficacy was noted for spouses in a previous report (Pinquart & Sörensen, 2005), however association between self-efficacy and traditional values for caregiving among spouses is unknown at present. Khalaila and

Litwin (2011) found that mastery a similar concept to self-efficacy, which is described as “the extent to which one believes that life choices are under one’s control, in contrast to being ruled by fate” (p. 681) was lower among women. The current sample is approximately three quarters female for caregivers, which could influence the association found. The effect size for this association was that 18% of the variance in self-efficacy was explained by CJCS, showing a moderate association.

5.1.3 Research question three discussion. Research question three asked ‘Are traditional values for family caregiving associated with caregiver well-being?’ The adaptational theoretical model would propose that characteristics of the caregiver [traditional values for caregiving, CJCS] would be associated with the caregiver’s adaptational outcomes, or well-being [CES-D and HSQ-12]. It is speculated through the available research that having higher traditional values for caregiving or being an ethnic minority caregiver can be associated with better adaptational outcomes. Two models tested traditional values for caregiving with the measurements of well-being [CES-D and HSQ-12]. The CES-D or depressive symptoms were not significantly associated with the CJCS, whereas the HSQ-12 was significantly correlated with the CJCS. One potential reason for this finding occurring could be the actual adaptational theoretical model itself. There is no direct relationship between characteristics of the caregiver and adaptational outcomes; this proposed relationship is through an indirect association through coping.

First, an explanation to why the CES-D yielded a non-significant result will be presented. Through the literature review it was discovered that findings regarding depression were mixed concerning whether the level of depression would be higher or lower depending on ethnic groupings of the samples (Dilworth-Anderson, et al., 2002;

Javenic & Connell, 2001; McCallum, et al., 2007; Sörensen & Pinquart, 2005). Losada, et al., (2010) reported that familial obligation a component of familism was related to increased depression levels. A study by Khalaila and Litwin (2011) reported that filial piety indirectly related to decreased depression. The CJCS includes items about both familism, and filial piety. These opposing effects on depression, could lead to the negative association found or lack of significant associations. However, this non-significant finding is also similar to some of the previous research in the field. Brummett, et al., (2012) in a recent study reported that the CJCS was not a significant predictor of depressive symptoms, which is a similar result to this thesis.

The HSQ-12 yielded a significant model and will be discussed. Bowling and Windsor (1997) reported that the HSQ-12 was supported and acceptable in use with older populations in Great Britain, which is similar to the sample from this study. Overall findings regarding physical health were mixed for different ethnic groups (McCallum, et al., 2007; Sörensen & Pinquart, 2005). McCallum, et al., (2007) reported that there was a difference between African American and White caregivers for reporting physical health; African American caregivers reported worse physical health. Familism is one of the components assessed on the CJCS. When looking at the concept of familism there is conflicting evidence; Knight and Sayegh (2010) indicate that familial obligations were associated with poor mental and subjective physical health, whereas, Liu et al. (2012) indicated specific to Chinese caregivers that familism appear to have a positive relationship to psychological health. The results of this study indicate that higher levels of traditional values for caregiving are associated with better subjective health, which is similar to Liu, et al. (2012). For every unit increase in CJCS, a 0.34 unit increase in HSQ-

12 is predicted when controlling for education. This model accounted for 9% of the variance, indicating that this model accounts for a small portion of the variance, a small effect. This result differs from Dilworth-Anderson, et al., (2004) which indicate that the CJCS had a curvilinear relationship to health. This curvilinear relationship means that caregivers who score lowest and highest on the CJCS had lower psychosocial health; while caregivers who scored moderately on the CJCS were associated with higher psychosocial health levels. In this study the CJCS appears to have a linear relationship to health and supports the adaptational theoretical model.

5.1.4 Research question four discussion. Research question four asked ‘Do caregiver coping resources and appraisal mediate the relationship between traditional values for family caregiving and caregiver well-being?’ This was tested through testing the adaptational theoretical model to see if coping resources mediated the relationship between the CJCS and HSQ-12. This also included the proposed models and plans for investigating if appraisal was a mediator variable.

In the first mediation test, coping resources was tested as a mediator variable between CJCS and HSQ-12. In the first model the MSPSS was the coping resources variable. It was found that both the beta weight and the beta significance decreased in this analysis. This model also produced a significant finding from the partial posterior (PP) method.

In the next mediation test with coping resources was tested as a mediator variable between CJCS and HSQ-12. In the second model the Revised Scale for Caregiver Self-Efficacy was the coping resources variable. It was found that the beta weight and the beta

significance decreased in this analysis. It also had a significant partial posterior (PP) method.

With both mediation models there is a small change in beta and significance levels. Both mediation models also had a significant partial posterior (PP) method indicating that mediation has occurred through two methods, which would support the adaptational theoretical model. The significance of this finding indicates that caregiving is a complex phenomenon.

The mediation results compares to the more recent research in the field, where more complex statistical models were tested. Lai (2010) tested filial piety as a moderator with stress appraisals and caregiver burden indicating that the traditional values for caregiving as measured through filial piety was able to explain some of the association from the model. Liu, et al., (2012) reported that the traditional values for caregiving as measured through familism had a positive indirect effect on caregiver's psychological health through coping and caregiver satisfaction.

To support the second mediation test that was proposed but was not conducted, a similar result was found from Brummett, et al., (2012). Brummett, et al., (2012) found that the CJCS and depressive symptoms were not significantly associated.

Through the last set of analyses, two models were created exploring the adaptational theoretical model tested to explore the combined and individual predicting effects of traditional values for caregiving, appraisal, and caregiver coping resources directly to the outcome variable of well-being (HSQ-12 and CES-D). In the first model well-being was the outcome variable (HSQ-12) used with all measures included (CJCS, NPI-D, MAASD-D, MSPSS, and Revised Scale for Caregiver Self-Efficacy) while

controlling for the effects of education. A statistically significant model was obtained ($p = 0.05$) and this full model accounted for 19% of the variance ($R^2 = 0.19$). Education was the only independent significant predictor indicating for every unit increase in education, a 3.02 unit increase in well-being is predicted (HSQ-12).

In the second model depressive symptoms was the outcome variable (CES-D) used with all measures included (CJCS, NPI-D, MAASD-D, MSPSS, and Revised Scale for Caregiver Self-Efficacy) while controlling for the effects of education. A statistically significant model was obtained ($p = 0.001$) and this full model accounted for 32% of the variance. The Neuropsychiatric Inventory Distress scale was the only independent significant predictor indicating for every unit increase in NPI-D, a 0.21 unit increase in depressive symptoms is predicted (CES-D).

Overall these analyses show that the adaptational theoretical model is supported from this sample of Canadian caregivers of PWD. Each model accounted for a significant portion of variance. This is an expected and welcome result, as this appears to indicate that the theory supports the combined associations that it claims.

5.1.5 Language related to cultural values. In caregiving research, language related to cultural values includes many terms researchers investigate, including: ethnocultural values, family values, and traditional values for caregiving. Using different language to explore relationships creates a difficulty in understanding what is being investigated. These terms have overlap in the some of the content that is being measured. The specificity of the terms is paramount for understanding the findings.

For interpreting the findings of this thesis, language is important. Through using traditional values for caregiving, which has been previously been defined as

incorporating items about filial piety and items about familism, is different from much of the reviewed research. Comparisons to previous research that have investigated their ‘cultural’ associations differently make it challenging to note either similarities or differences.

5.2 Study Limitations

There are several limitations that must be noted from the thesis research study. The limitations for this study relate to: (1) sample size; (2) sampling; (3) measurements and; (4) theoretical error.

The sample size was small, making it difficult to detect modest relationships as previously discussed in Chapter 3. This study may not have had enough statistical power to find an association. Traditional values for caregiving were hypothesized to have modest associations to the theoretical model. Pinquart and Sörensen (2005) support the notion that traditional values for caregiving could have modest associations indicating that “it is important to note that, although a number of statistically significant ethnic differences emerged in the present meta-analysis, many differences were quite small and should not, therefore, be over interpreted” (p. 102).

Using a convenience sampling approach is subject to bias. For this sample all participants were receiving some type of formalized service. This bias does limit the ability to generalize the results to the rest of the population and makes the results tentative. The results are also tentative because this study was conducted as exploratory research.

The measurements that were used of this study could be questioned relating to statistical power through precision. It is unknown with any scale but especially the newer

scales (CJCS and MAASD) if they accurately are measuring the concepts they claim to. One study indicated (Dilworth-Anderson et al., 2004) that the CJCS had a curvilinear relationship with psychosocial health. If this is true, it would be difficult to interpret the findings because this study investigated all variables as linear. For this study when the scatterplot was created to assess for linearity of the CJCS, there was no apparent reason to consider that the association was a quadratic function.

Restricting the range on the demographic characteristic of education from a 7-point scale to a 3-point scale is a possible limitation. By decreasing the amount of choices for education there is less precision and a possibility of error.

Using the adaptational theoretical model of stress and coping for the research study can be a limitation. Even though the stress and coping model is widely used in caregiving literature, there were some adaptations made to the model. The adaptations that were made to the model may not be correct. If the theoretical model selected for the research study is not correct then it would be difficult to find associations or the 'truth.' Based on the findings from research question one, that there was no association of the CJCS predicting appraisal after controlling for education; can be concluded with two possible outcomes. The first outcome would be that these findings are the 'truth' or that these findings are incorrect.

Not including subgroup analyses is a limitation of the current thesis. Due to the lack of variability from the sample and lack of group membership in some of the subgroups; subgroup analyses were not able to be conducted. This limits the understanding of the adaptational theoretical model to explore the relationships between

groups; the level of traditional values for caregiving as well as, the other measures between groups; and a comparison of subgroup results to entire sample results.

5.3 Future Recommendations

The current master's thesis results need to be used with caution and are tentative. This research project was exploratory research. This research project did not separate the sample into different groups based on a racial, ethnicity, or cultural basis, which previous research work has done. The next steps following this study will now be presented, for future research. This calls for this project to be conducted again with a larger sample size to examine if there are modest relationships between traditional values for caregiving with the adaptational stress and coping model that were investigated through this exploratory study. It is urged for the next project to use a divergent method whereby the sample will be analyzed using the entire sample as well as analyzed separating the sample into various groups to assess for mean differences. Through research the theoretical model and associations appear to be the same between different sub-groups. Through not separating the sample into groups allows for the in-group variation of cultural values to be assessed; and come to a greater understanding of traditional values for caregiving and its relationship to the stress and coping model for future service planning and increase knowledge.

The CJCS along with other separate measures of filial piety and familism should be used to investigate the future sample of caregivers. Knight and Sayegh (2010) have proposed that filial piety and familism have opposing effects on one another. This would allow for the CJCS measurement to be assessed as well as the proposed associations that

Knight and Sayegh (2010) have presented. This would also critique the clarity of the CJCS and its use for capturing traditional values for caregiving.

A measure of coping should be included in future studies. This would allow for further testing of relationships of the theoretical model and how the variables interact with one another. In conclusion more research is needed regarding caregivers of persons with dementia and traditional values for caregiving.

5.4 Practice Implications

Practice implications from this study are at the beginning stages. More research is needed to enter clinical practice.

An interesting result between traditional values for caregiving and self-efficacy was found. This relationship had a negative association. Confirming this result with further research might indicate that caregivers of PWD with high levels of traditional values for caregiving might need supports for self-efficacy. This would help to increase their confidence in their caregiving tasks and role.

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Appendices:

Appendix A: Basic Demographic Face Sheet

CG OHIP # : Yes=1, no=0

Gender

1 = Male

2 = Female

Age – all ages left as entered (didn't code)

Caregiver Relationship to Care Recipient

- Made sure response was in reference to Care recipient. I.e. The caregiver is the care recipient's *daughter*; therefore, response to the question is *daughter* and not mother (answer is coded as 2)
- Used 4 Categories:
 - 1 = Spouse or partner
 - 2 = Children
 - 3 = Relative → grandmother, niece/nephew, daughter-in-law
 - 4 = Non-relative

DFS1 – Country of Origin

(Note: Countries categorized according to www.nationalgeographic.com)

1 = North America

- Canada
- Trinidad
- United States

2 = South America

- Guyana

3 = Eastern Europe or ex-Soviet Union countries

- Czech Republic
- Estonia
- Greece
- Hungary
- Poland
- Romania

- Lithuania
- Macedonia
- Malta
- Slovenia
- Ukraine

4 = Western Europe

- Germany
- Italy
- United Kingdom
- Sweden
- Austria

5 = Israel

6 = Middle East Arabic

7 = North Africa

8 = South Africa

9 = Asia

- Pakistan
- Philippines

10 = Other (Caribbean)

DFS1a

- Immigration Date:
 - 1 = 1910 – 1930
 - 2 = 1931 – 1950
 - 3 = 1951 – 1970
 - 4 = 1971 – 1990
 - 5 > 1990

DFS2 - Ethnicity

- Ethnic divisions done according to divisions used in DFS1 (Country of origin)
- Note: Coded different/out of place responses according to participant's Country of origin
 - 'Black' – coded as other
 - 'Muslim' – coded as other
 - 'White Anglican' – coded as Canadian
 - 'White/Caucasian' – coded as other

- Codes:
 - 1 = Jewish
 - Israeli
 - 2 = Eastern European
 - 3 = Western European
 - 4 = Canadian
 - Includes Canadian plus category 1/2/3 e.g. 'German Canadian'
 - 5 = other
 - East Indian
 - Pakistani
 - Philipino

DFS3

- Blank responses were coded as 0 = "no religion"
- Codes:
 - 0 = No religion
 - 1 = Catholic
 - 2 = Protestant
 - 3 = Jewish
 - 4 = Muslim
 - 5 = Other (high Anglican, Wiccan, United Church, Presbyterian, Baptist, Lutheran)

DFS4 Occupation

- Codes
 - 1 = Higher executive: major professional
 - 2 = Business manager: lesser professional
 - 3 = Administrative personnel: minor professional
 - 4 = Clerical and sales worker, owner of a little business, technician, teacher
 - 5 = Skilled manual employee
 - 6 = Machine operator, semi-skilled employee
 - 7 = Unskilled employee on welfare, unemployed, retired, homemaker

DFS5 Education➤ Codes:

- 1 = graduate professional training
- 2 = standard college or university
- 3 = partial college training
- 4 = high school graduate
- 5 = partial high school training
- 6 = junior high school
- 7 = <7 years of schooling

DFS6

- a = 1, b = 2, c = 3, d = 4, e = 5

DFS7

- 1 = Married
- 2 = Common Law Union
- 3 = Single
- 4 = seperated
- 5 = Divorced
- 6 = Widowed

DFS8

Question was not coded and disregarded for analysis

DFS9

Yes = 1, No=0

DFS10

- Left age as entered (did not code into categories). Ages not known/entered were left blank
- Relationship to caregiver was divided into 6 categories:
1 = son/daughter (includes step-son/daughter)

2 = sister/brother

3 = parent

4 = in-laws

5 = extended family (aunt, uncle, cousin, grandparents)

6 = other (spouse, friend, god-parents)

- Frequency was left as is (did not code into categories)

DFS11

Yes=1, no=0

DFS12

Yes=1, no=0

DFS13

- Response measured in years (did not code into categories)
- If response was 2-3 years, then it was entered as 2.5 years
- 'Couple years' = 2 years

DFS14

- Response measured in hours. Input number only (i.e. 24 not 24h)

Appendix B: Zero Order Correlations Table

	CJCS	CES-D	HSQ-12	MSPSS	Revised Scale for Caregiver Self-Efficacy	MAASD	NPI	Education
CJCS	<i>R</i> 1 <i>Sig.</i>	<i>R</i> -0.04 <i>Sig.</i> 0.73	<i>R</i> 0.20 <i>Sig.</i> 0.09	<i>R</i> 0.25* <i>Sig.</i> 0.03	<i>R</i> -0.40** <i>Sig.</i> 0.001	<i>R</i> 0.04 <i>Sig.</i> 0.72	<i>R</i> 0.53 <i>Sig.</i> 0.65	<i>R</i> -0.05 <i>Sig.</i> 0.69
CES-D	<i>R</i> -0.04 <i>Sig.</i> 0.73	<i>R</i> 1 <i>Sig.</i>	<i>R</i> 0.20 <i>Sig.</i> 0.09	<i>R</i> 0.30** <i>Sig.</i> 0.01	<i>R</i> -0.42** <i>Sig.</i> 0.0001	<i>R</i> 0.40** <i>Sig.</i> 0.0001	<i>R</i> 0.48** <i>Sig.</i> 0.0001	<i>R</i> -0.13 <i>Sig.</i> 0.28
HSQ-12	<i>R</i> 0.20 <i>Sig.</i> 0.09	<i>R</i> 0.20 <i>Sig.</i> 0.09	<i>R</i> 1 <i>Sig.</i>	<i>R</i> 0.28* <i>Sig.</i> 0.02	<i>R</i> -0.30* <i>Sig.</i> 0.01	<i>R</i> 0.10 <i>Sig.</i> 0.40	<i>R</i> 0.08 <i>Sig.</i> 0.48	<i>R</i> 0.19 <i>Sig.</i> 0.10
MSPSS	<i>R</i> 0.25* <i>Sig.</i> 0.03	<i>R</i> 0.30** <i>Sig.</i> 0.01	<i>R</i> 0.28* <i>Sig.</i> 0.02	<i>R</i> 1 <i>Sig.</i>	<i>R</i> -0.45** <i>Sig.</i> 0.0001	<i>R</i> 0.30** <i>Sig.</i> 0.01	<i>R</i> 0.29* <i>Sig.</i> 0.01	<i>R</i> 0.09 <i>Sig.</i> 0.44
Revised Scale for Caregiver Self- Efficacy	<i>R</i> -0.40** <i>Sig.</i> 0.001	<i>R</i> -0.42** <i>Sig.</i> 0.0001	<i>R</i> -0.30* <i>Sig.</i> 0.01	<i>R</i> -0.45** <i>Sig.</i> 0.0001	<i>R</i> 1 <i>Sig.</i>	<i>R</i> -0.33** <i>Sig.</i> 0.01	<i>R</i> -0.43** <i>Sig.</i> 0.0001	<i>R</i> 0.14 <i>Sig.</i> 0.27
MAASD	<i>R</i> 0.04 <i>Sig.</i> 0.72	<i>R</i> 0.40** <i>Sig.</i> 0.0001	<i>R</i> 0.10 <i>Sig.</i> 0.40	<i>R</i> 0.30** <i>Sig.</i> 0.01	<i>R</i> -0.33** <i>Sig.</i> 0.01	<i>R</i> 1 <i>Sig.</i>	<i>R</i> 0.50** <i>Sig.</i> 0.0001	<i>R</i> 0.12 <i>Sig.</i> 0.30
NPI	<i>R</i> 0.05 <i>Sig.</i> 0.65	<i>R</i> 0.48** <i>Sig.</i> 0.0001	<i>R</i> 0.08 <i>Sig.</i> 0.48	<i>R</i> 0.29* <i>Sig.</i> 0.01	<i>R</i> -0.43** <i>Sig.</i> 0.0001	<i>R</i> 0.50** <i>Sig.</i> 0.0001	<i>R</i> 1 <i>Sig.</i>	<i>R</i> -0.06 <i>Sig.</i> 0.59
Education	<i>R</i> -0.05 <i>Sig.</i> 0.69	<i>R</i> -0.13 <i>Sig.</i> 0.28	<i>R</i> 0.19 <i>Sig.</i> 0.10	<i>R</i> 0.09 <i>Sig.</i> 0.44	<i>R</i> 0.14 <i>Sig.</i> 0.27	<i>R</i> 0.12 <i>Sig.</i> 0.30	<i>R</i> -0.06 <i>Sig.</i> 0.59	<i>R</i> 1 <i>Sig.</i>

*Sig. (2-tailed) at the 0.05 level

**Sig. (2-tailed) at the 0.01 level